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ABSTRACT

This collection of 16 papers attempts to provide a comprehensive overview of the state of children in the nations of the Americas. The collection's five sections examine children's rights, perspectives of five parents from five different nations, children with disabilities in the legal system, promoting the rights of children through social policy, and strengthening communities through policy and program initiatives. A case vignette completes each section. The papers are: (1) "The Rights of Children and Economic Prosperity: Competing Claims?" (Rodrigo Carazo Odio); (2) "How To Be a Child and Not Die in the Process" (Eugenia Maria Zamora Chavarria); (3) "Fighting for Our Rights" (Humberto Jordano Quintero); (4) "Stronger Families--Stronger Society" (Roberto Leal Ocampo); (5) "Social Policy and the Support of Families" (Aminta Sprockel); (6) "Challenging the System: The Parent's Struggle" (Paulette Berthiaume); (7) "Creating a Vision: The Rights of Children in Jamaica" (Paulette Brown); (8) "Access to Justice and Children with Disabilities" (Tanis Doe); (9) "The United Nations Convention on the Rights of the Child: A Tool for Advocacy" (Diane Richler); (10) "The Rights of Children with Disabilities to Medical Treatment: The Canadian Scene" (Andre Blanchet); (11) "Inclusive Child Care in Canada: Advances at Risk" (Sharon Hope Irwin); (12) "Learning from Our Experiences in Education Policy: The Story of Segregated Schools in the United States" (Michael Remus); (13) "Services That Hurt and Services That Help" (Michael Mendelson); (14) "Strengthening Communities through Policy and Program Initiatives: The Latin and Caribbean Reality" (Ana Maria Damini de Frappola); (15) "Concepts of Development and Maturation: Barriers to the Rights of the Child?" (Luis Lopez Molina); and (16) "Policy As If Disability Mattered" (Melanie Panitch). Some papers contain reference notes. The following vignettes are also included: "Andrew" by Barbara Nish; "Oliver" by Colette Savard; "Rashaad" by Zuhy Sayeed; and "Ralph" by Lorraine Silliphant. (DB)

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As If Children Matter

Perspectives on Children, Rights and Disability

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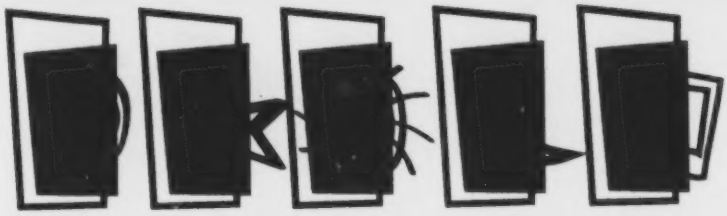

As If Children Matter

Perspectives on Children, Rights and Disability

L'Institut Roeher Institute in collaboration with Partnerships in Community Living

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This book is drawn from presentations given by participants in the Partnerships in Community Living project at the Stronger Children — Stronger Families 1994 International Year of the Family Conference on the United Nations Convention on the Rights of the Child.

Partnerships in Community Living

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Partnerships in Community Living

The Canadian Association for Community Living (CACL), the Inter-American Children's Institute (IACI) and the Inter-American Confederation of the International League of Societies for Persons with Mental Handicap (CILPEDIM) have formed a partnership with the vision to change social policy for children and youth with disabilities in the Americas. The project is funded by the Canadian government under Health Canada through the Children's Bureau.

The project goal is to promote the inclusion of children and youth who have a disability in their communities and in the social policy of their countries. The project objectives are: to involve and train children and youth with disabilities, their families, their associations and their governments in the creation of a framework and a strategic plan for the promotion and design of new social policies and service delivery systems, while fostering a partnership and cooperative action between the non-governmental and governmental sectors; to develop an analysis of the state of policies and programs and to present options for future policy reform in relation to children and youth who have a disability in the Americas; to develop an information and resource network available to children who have a disability, their families, professionals and planners.

Out of the first conference of the project came the Declaration of Managua, which states that "to ensure social well-being for all people, societies have to be based on justice, equality, equity, inclusion and interdependence, and recognize and accept diversity. Societies must consider their members, above all, as persons, and assure their dignity, rights, self-determination, full access to social resources and the opportunity to contribute to community life."

The three main activity areas of the project are: information, training and research. Information centres are currently being developed in nine countries throughout the region with coordination by the IACI in Montevideo, Uruguay, and l'Institut Roeher Institute in Toronto, Canada. Regional training and development seminars will follow up on and plan the implementation of the Declaration of Managua. Research is being done on policies and programs.

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Partnerships in Community Living

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FOREWORD

As If Children Matter: Perspectives on Children, Rights and Disability is both a testament and a challenge. It is a testament to the rights of children who have a disability, to their families and advocates and to their struggles to achieve and exercise those rights. It is a challenge to give meaning to the *United Nations Convention on the Rights of the Child* and, in particular, to assure that children are not more at risk of an infringement of their rights because of disability. The *Convention*, in recognizing the specific vulnerabilities and needs of children with disabilities, extends specific protection to the rights of these children.

As If Children Matter is a compilation of presentations made at the Stronger Children — Stronger Families conference in Victoria, British Columbia, Canada, in June 1994. The conference was organized as a part of Canada's efforts to support the implementation of the *Convention on the Rights of the Child*. These presentations, which formed a conference stream on disability, drew from the Partnerships in Community Living project, funded for three years by the Children's Bureau of Health Canada. This project is being carried out by the Canadian Association for Community Living (CACL), the Inter-American Children's Institute (IACI) and the Inter-American Confederation of the International League of Societies for Persons with a Mental Handicap (CILPEDIM) with technical support from l'Institut Roeher Institute and School District 12, Woodstock, New Brunswick. These partners have joined together to promote the inclusion of children and youth who have a disability in the social policy of the nations of the Americas. The project's objectives are community development, research and the dissemination of information to help build societies based on justice, equality, equity, inclusion, interdependence and the acceptance of diversity.

The contributors to the book, many of them leaders in the Partnerships project, draw on a vast and varied array of experiences to give a comprehensive, and often distressing, overview of the state of children in the nations of the Americas. Their experiences range from the international political arena to the realities of day-to-day life as parents.

The first section examines children as a rights issue, led off by Rodrigo Carazo Odio, former President of Costa Rica. He addresses the issue of children's rights from a broad global perspective, examining the impact of technological advances and the preoccupation with economic prosperity on families today. He calls for a return to spiritual and creative values, beginning with the recognition that "children are the hope and the responsibility of the human race", to balance the destructive forces of a market-driven economy.

Eugenia Maria Zamora Chavarria looks at the appalling conditions of life for the 195 million children and youth in Latin America and the Caribbean. To better understand how children are seen in today's societies, she draws on historical perceptions of children from 1909 onward, from the children of immigrants who were thought to "have no notion of their duties as human beings" to post-war societies that feared "dangerous children" as a threat to their new stability.

Humberto Jordano Quintero of Managua, Nicaragua, tells of his experiences as a young man labelled as having an intellectual disability. In moving detail, he openly describes his hopes and aspirations, despite the doubts and expectations of failure that surround him. His happiest moment, he says, is when he feels he is being treated and respected as a person.

The following section, Strengthening Families through Policy Initiatives, features perspectives of five parents from five different nations. Roberto Leal Ocampo of Nicaragua looks at the situation of families from a broad social perspective. Like Rodrigo Carazo,

he sees a breakdown of traditional community values caused by increasingly fast-paced, individualistic societies. Communities, he says, have lost their dreams and their sense of romanticism. He sees families as the source of hope in restoring positive values and attitudes.

Aminta Sprockel relates her experiences as mother of Josette, her daughter who has Down syndrome. She identifies the attributes of families that create acceptance of, and a positive attitude towards, life with a child who has a disability. In her experience, early intervention and infant stimulation are the key to supporting families, especially when they are offered as an education and a philosophy from which the extended family can benefit.

Paulette Berthiaume's story of parenthood is the story of struggle to free her son from an institution. It speaks of government departments and medical professionals insensitive to the realities and needs of families. It speaks of a system that treats her son as worse than a criminal, for as she says, "If I was an offender, I would serve my term and out I would go." However, there was no end in sight for her son Louis's imprisonment. In the end, she says, parents must continue to stand and fight for the rights of their children.

Finally in this section, Paulette Brown of Jamaica presents another family reality, one of poverty and lack of education exacerbating the challenges of life with a child who has a disability. Paulette's indominable spirit is evident as she recounts the many creative ways she found to build a support network and opportunities for her daughter, Shanique, in a country where services are practically non-existent.

On the subject of children with disabilities in the legal system, Tanis Doe looks at the particular obstacles children with disabilities must overcome in gaining access to justice. She outlines their multiple levels of vulnerability as individuals disempowered first by their status as children and second by their

diagnosis of disability. She then details the barriers they face in gaining access to justice as people with possible communication barriers. Can the courts accommodate child witnesses with extremely challenging disabilities to present their case in court? This is a vital responsibility of society, she asserts, in order to deliver the message that children with disabilities are not "prosecution-proof" victims.

Diane Richler examines cases in Canada in which the rights of children with disabilities have not been recognized, which, in one situation, caused a child's death. She calls on the government of Canada to close the gap between the rights it has endorsed in the *UN Convention on the Rights of the Child* and the reality of life for children with disabilities and their families in Canada. She identifies the *UN Convention*, the *Canadian Charter of Rights and Freedoms* and other human rights documents as tools for advocacy to be used in insisting that the rights of children with disabilities in Canada be respected and protected.

In the following section on promoting the rights of children through social policy, André Blanchet examines specific Canadian cases to illustrate the state of children with disabilities and their access to medical treatment. He identifies attitudes in the medical culture and a lack of knowledge by physicians about legal precedents as factors contributing to situations where children are denied medical treatment they would have received if they had not been identified as having disabilities.

Sharon Hope Irwin examines the lack of Canadian social policy in early intervention and child care — policies that are essential for promoting the rights of children with disabilities. In the absence of legislation, she traces the process that advocates and parents have followed in securing early intervention and day care for their children and how, in this way, they have forced the government to take the first steps towards actually creating policy.

"Don't do what we did," is the message Michael Remus delivers from the United States in recounting how misinterpretation of the country's education law resulted in the establishment of segregated education facilities. He details a 15-year battle to reverse the damage and have the original intent of the law, inclusive education, become reality. The lesson, he observes: be conscious and careful of wording in legislation and anticipate any misinterpretations up front.

The final section, Strengthening Communities through Policy and Program Initiatives, is led off by Michael Mendelson's comprehensive article on how social policy can be used to either strengthen or disempower communities. Drawing on examples from Canada's treatment of Native Canadians in the 1960s, he shows how the basic attitudes and presumptions of people creating and delivering policy profoundly affect the lives of service recipients. Basic principles for social policy that strengthens communities are clearly articulated.

Ana María Frappola details social factors that have led to discrimination against, and segregation of, people with disabilities in Latin American and Caribbean countries. She identifies the need for a new model of inclusive services for families. Her step-by-step proposal for achieving this objective carefully outlines the roles of different players in the process.

In a thought-provoking article, Luis Lopez of Costa Rica explains how the common perspective of children as pre-adults, lacking in adult maturity and complete development, is a barrier to their rights. "Is it not simply their condition as people in particular and unique states of development and maturation that identify children and give them access to special rights?" The rights of children with disabilities are particularly threatened by this perspective as they are seen as people who will never reach that full stage of development most valued in society.

In the final article, Melanie Panitch suggests looking at disability issues "as if disability mattered". From this perspective she examines the state of child care in Canada and how it functions, or fails to function, for families, particularly families that have a child with a disability. She then looks at the entire gammit of social policy that could benefit from changes implemented "as if disability mattered."

Woven into these chapters are stories told by parents in Canada — their personal experiences of having a child with a disability. These stories illustrate what a lack of rights means in the lives of their children — the exclusion and rejection for their children and the frustration, despair and anger they experience as parents. Their stories are positive, however, as the parents decribe how they found exceptional love and strength in their families as a result of their challenges or a new dimension of acceptance in themselves and their communities for their children.

It is hoped that this collection of articles will be part of a new and growing dialogue on the rights of children, particularly those with disabilities. We would like to thank the Children's Bureau, Health Canada, for generously funding the translation and printing of this collection in English and Spanish. We would also like to thank the contributors who travelled from far and wide to bring their stories to Victoria. Special thanks go out to the organizers of the Stronger Children — Stronger Families conference, particularly Sandra Griffin, who provided the impetus for this collection of articles. And, finally, thanks are extended to the partners in the Partnerships for Community Living project, IACI and CILPEDIM, for their dedicated contribution to the objectives of the project.

Diane Richler
Executive Vice President
Canadian Association for Community Living

SECTION I.

CHILDREN — A RIGHTS ISSUE

What is the state of children and youth in the nations of the Americas and around the world? What factors affect their well-being? In this section, international leaders in human rights challenge the boundaries of human rights initiatives to promote the well-being of children and youth.

CHAPTER 1.

The Rights of Children and Economic Prosperity: Competing Claims?

BY RODRIGO CARAZO ODIO, COSTA RICA

Around the world today, rapid technological developments and other profound changes have affected people's social behaviour, motives and aspirations and have brought an early beginning of the third millennium. The economic centre of the world is moving westward, continuing the trend that began centuries ago. Over the course of human history, the social and economic centre of the world has moved from the Mediterranean to the Atlantic, from Mesopotamia to Egypt, Greece, Rome, Spain and then England. Today the centre is moving across North America to the Pacific Ocean.

This process is dynamic and is occurring simultaneously with the decline of the economic and political centres that have guided the world in the recent past. Consequently, for example, the far East is less and less Eastern every day.

Technology continually alters human activity. Today, it is not just humans and animals that work. Machines and robots facilitate human efforts that produce goods and services. Technological advancements and the progressive liberation of humans from physical labour have made the intelligence and the creative capacity of human beings more significant.

In this process, societies have become so focused on, and pressured by, technological advancements that our time is taken up with simply keeping abreast of these technologies. Never before has humanity been so dependent on modern advances, which have transformed the world into an ongoing global classroom. As a result, we have lost sight of the physical reality around us and are unable to conceive of the destruction of the planet through these technologies and our other material pursuits. However, as we all know, the environment is vulnerable to abuse and destruction when cultural development, spirituality, beauty, art and love are neglected.

In the last three decades, humanity has experienced more material changes than since the beginning of humankind. We have lost our capacity to be amazed by technological achievements. As a result, we have lost sight of former values and have failed to integrate them into our modern values.

The past, both distant and recent, is an accumulation of humanity. I am confident that human beings will be able to direct their development and education so that, in the coming century, a new culture will be created, inspired by the will of humanity to improve. The goal of this development must be the elimination of poverty, the achievement of justice and the validation of peace.

Today, our state of interdependence calls for harmony between peoples and between nations. If this state of harmony can be achieved, both within each individual human being and in their communities, peace will be possible. We have to be prepared to welcome the coming century in a creative and positive spirit. We have to be aware of the need to bring with us positive values from the past, which can be processed and integrated according to our modern perspective, because life is a continuous process of development.

Although technology and the application of scientific knowledge deserve attention, their teaching must be accompanied by attention to the Humanities and the Arts as tools of intellectual

development and cultural enrichment — of education. This education must begin with the conviction that children are the hope and the responsibility of the human race. The value that children represent has to be part of society's daily reality and must generate an effective commitment to the objectives of the World Summit for Children and the goals of the *United Nations Convention on the Rights of the Child.*

The future will be the result of our attitudes and efforts in the present. Because of the rapid changes we are experiencing today, we must promote a change in our personal attitudes and in those of governments and societies. Because of today's reality, we must be committed to resolving our social problems to prevent them from having a negative impact on our children.

The current socio-economic model creates an odd situation where humanity has been put into the service of the economy instead the economy being managed for the benefit of human beings. Merchandise has priority and the competitive style of merchandise production is vulnerable to economic activity. A stable economy is considered the most important achievement in every country, along with the stability of currency and — something considered fundamental — the opening of our markets to suppliers worldwide.

To be productive competitively, salaries are fixed or even frozen. The treasury attracts and stimulates corporations by offering large subsidies and tax concessions. To attain economic stability and cover these expenditures, funds directed to social concerns, including health and education, are reduced in the national budget. An increase in exports is stimulated at the cost of people's quality of life, their health, well-being, their children's nutrition and education and the care of children with disabilities.

Since the state's financial investment in people's health is insufficient, the privatization of essential health services is promoted. There is the risk that health services will eventually

fall completely into the hands of the private sector, becoming a service paid for directly by users. This, in effect, makes these services inaccessible to the most needy and poorest sectors of the population, threatening their health.

The key objective of today's public administrations is to pretend that the country is becoming wealthier, hiding the fact that this wealth comes at the cost of the impoverishment of the people. Consequently, we have countries that seem rich but are full of people living in misery.

With policies oriented to improving the economy — a goal considered acceptable if it satisfies the needs of business and the objectives of international financial institutions — the division between classes is strengthened. The privileged groups grow wealthier and yet protest that the state gives "favours" to people fighting for fair salaries and the possibility of better lives.

The socio-economic structure of our countries in the last 10 years has been marked by the abandonment of agricultural activities. This abandonment, caused by an open market economy in which our farmers cannot compete, produces explosive growth of already crowded cities. The resulting "barrios" or suburbs lack essential public services and are full of people from the countryside who are malnourished and have no education. Diseases such as cholera, dengue fever and tuberculosis proliferate, along with social problems such as drug addiction, alcoholism, prostitution — including child prostitution — crime, violence, unsafe cities and emerging gangs of teenagers who are criminals from an early age, similar to the phenomena seen in North America.

Phenomena that were shocking years ago are now commonplace: child murderers and thieves; girls becoming mothers at an early age because of sexual abuse by their relatives or because of the environment in which they live; children from

broken families who, as a result of our troubled society, leave their families to become a new social class: "street children".

The economy-driven society has embarked on a downward spiral. Every day, it produces more marginalized and unhealthy people, more street kids, more school dropouts, more young mothers, more juvenile delinquents, more prostitutes, drug addicts and alcoholics. Society is guided by modern economists who say, without shame, that their only concern is the improvement of the economy, regardless of the lives or destinies of millions of "corn growers". These "corn growers" are people who are left without livelihoods because they are squeezed out of production by the competition of imported, subsidized corn. When one sector of society is forced under, the quality of life in general is lowered; services are decreased, taxes are raised and services in hospitals deteriorate. As people's capacity to buy basic goods decreases, official charities appear to fulfill people's needs, providing food, clothing and shelter.

As the quality of education diminishes, there is an abundance of cheap labour. The distribution of charity (welfare) proves this new perception, that poor people and unemployed farmers are an obstacle to development that "should" disappear. Collective impoverishment increases the incidence of malnutrition and lack of education. People have less and less capacity to nourish and educate their children.

Meanwhile, economists proclaim the increase of what they call "per-capita income", hiding the fact of the concentration of wealth in few a hands which leaves the majority of the population to rely on charity. Without shame, the poor receive what is left over from the wealthy.

I believe that whoever sees this reality has the duty to call it as it is: extreme, growing misery and extreme wealth becoming concentrated; wealthy groups who have increasing power over production of goods, which they privatize as much as possible.

Let us stop increasing the numbers of uneducated, poor, sick, undernourished people. The moment for justice has come.

It is urgent that responsible, capable citizens create an economic model in which children are educated and nourished as the first step in improving the overall standard of life. In many countries today, the standard of living is worse than in the days of slavery, when slave owners always fed their slaves so they could work harder. Today, slave owners seek those with more strength, pushing aside those who are undernourished and uneducated, condemning them to permanent unemployment, poor health, a miserable subsistence and illegal activities.

A model of justice has to emerge from the certainty that, in this world, there should be enough for everyone or nothing for anyone. At the same time, this model of justice has to emerge from a respect for moral values, for human rights and for Christian principles. With competitiveness prevailing over people's well-being, there is convincing evidence that the moment has come to change the model or witness the collapse of society.

The new model has to revive human rights and eliminate charity. A fair society will become a reality not through macro-economics but through the just treatment of its people, especially its children. The purpose of people's being is to create a better future for their children: it is to children that we are in debt and they are dependent upon adults for the opportunity to live in hope.

The purpose of civil and political organizations is to ensure happiness and well-being for all members of a state. Governments should not try to hide from their obligations. In signing the *Convention on the Rights of the Child*, they assumed obligations; they must put the *Convention* into practice. They must find and implement solutions to the problems created by the abuse of large sectors of the population. They must eliminate the causes of marginalization, including injustice, ignorance and misery.

More than 60 per cent of the population of Latin America experiences hunger and desperation. Eighty per cent suffer from a lack of social services, in addition to the unemployment affecting more than 100 million workers. All this is found in an environment where there is a housing shortage for 100 million people and where 85 per cent of our children suffer from malnutrition. One-hundred million children live on the streets in our world. This means we, members of the government and society, live a painful reality that demands our action. States are obligated to ensure the enactment of the *Convention*. Rich states are obligated to end the exploitation that impoverishes the world.

We have to reiterate the credo that should guide our lives, the society in which we live and the state that rules us. It is our duty to dedicate ourselves to the realization of objective of the World Summit for Children and the goal of the *Convention on the Rights of the Child*: "Let us prepare the child for a responsible life in a free society."

CHAPTER 2.

How to Be a Child and Not Die in the Process

BY EUGENIA MARIA ZAMORA CHAVARRIA, URUGUAY

The Inter-American Children's Institute is a specialized organism of the Organization of American States (OAS). Our Institute was founded in 1927 and our headquarters are located in Montevideo, Uruguay. The Institute was created with the specific objective of promoting and reinforcing awareness of the problems affecting children of the American continent.

The Institute carries out research, training, technical assistance and gathering and dissemination of information. The Institute's structure includes: the Pan American Child Congress, which has been held 17 times since 1909, the most recent being in Costa Rica in 1993; the Directing Council that includes governmental delegates of 34 OAS-member countries; and its office in Montevideo, Uruguay.

The Organization of American States is controversial, has faced a variety of problems and has received much criticism. However, we feel it is a very important political organization. It provides a venue for the political realities of our continent to be expressed and it provides communication lines for south-south dialogue and north-south dialogue.

My colleagues and I at the Institute perform a function that goes beyond the formal mandate. We communicate with Canada, Central America, the "southern cone" countries of South America and the English, Spanish and French Caribbean. We also communicate with Europe and other regions.

We communicate as a legitimate organization representing countries of great diversity and contrasts. On the South American continent, there are pure Welsh cultures in the province of Chubut, in the Argentinean Patagonia, where school children are red-headed and blue-eyed, sing in Welsh and have their five o'clock tea in the best Welsh style. From there we can move to the Bolivian or Ecuadorian highlands or the Andean zone and find indigenous Quechuas or Aymaras. And from there we can move to Jamaica, the English Caribbean or the Atlantic Central American coast and other regions of the United States and Canada where we find black cultures of African origin.

We represent countries with such great geographical contrasts as Brazil and Haiti. These are countries with a variety of political situations, from independent sovereign nations to insular territories that are not yet sovereign or independent. They are countries with many different languages and dialects. There are not only the aboriginal languages of Canada, which also has English and French, not only the Spanish of Spanish-descended Americans, but also the vernacular of Latin American cultures such as Quechua, Aymara and a series of dialects that conserve the richness of original African languages, found in Mosquitia on the coast of Honduras. Finally, they are countries with very poor areas and very rich areas — not only the industrial north — Canada and the United States — but also the south with their visible contrasts, as between Haiti, Brazil or Mexico.

Within this rich diversity — so varied and complex — I would like to address what is happening right now in the area of children's issues, in Latin America and the Caribbean in

particular, based on the perspective of global economic forces that affect families and children. The Institute drafted a document which we hope will be a priority on the political agenda at the OAS General Assembly in 1995. A section of this document has the ironic title: "How to Be a Child in Latin America and the Caribbean and Not Die in the Process". This is borrowed from the title of a famous Spanish movie, How to Be a Woman and Not Die in the Process. The document points out that approximately 840 million people live in the lands extending from Alaska to Patagonia, the promised land of integration. One third of that total lives in the United States and Canada, the only developed countries of the Inter-American system. The balance, 448 million people, live in the Latin American and Caribbean developing nations.

The Convention on the Rights of the Child defines a child as any human being under 18 years of age. According to this definition, we have 195 million children and youths in Latin America and the Caribbean. That is, 45 per cent of the Latin American population is younger than 18 years. Unfortunately, most of these children — 120 million — do not enjoy the rights approved by the *Convention*, beginning with the most basic one: the right to survival. Evidence indicates that being a child in Latin America and the Caribbean is far from an innocent game in this "adultocratic" culture. Of every thousand babies born alive, 78 die before reaching the age of five. This mortality rate is seven times higher than that of the United States or Canada. It is estimated that more than four million children under five years of age die every year from diarrhea and more recently from cholera, once eradicated from the continent.

For children who are able to escape these mortal traps — those who live through the first five years of life — there lurk general socio-economic obstacles and cultural marginality. These exclude children and youths from the benefits of economic and

cultural development. This situation causes the visible and growing Latin American urban drama — children living in the streets. Behind this reality, ECLAC, the Economic Commission for Latin America and the Caribbean, estimates that 34 million households exist in conditions of critical poverty. The inhuman conditions in which millions of Latin American children live are a flagrant violation of the most basic human rights. The exclusion of these children from social, economic and cultural benefits of development has profound political implications. It is the denial of the essence of democracy: participation, equity and social justice.

In addition to defining the socio-economic conditions, we have also tried to define the evolution of Latin American thought about children's problems in this century. Images of childhood have been seen in the context of judicial, social, educational and sanitation issues. In other words, we have tried to interpret the universal rights put forth in international documents according to the practices, institutions and cultures of our region. Historical analysis of the American ideas about children was facilitated by documentation from 16 Pan American Child Congresses that have taken place since 1916. The Congress, the oldest intergovernmental regional forum, is a unique process created by American countries to analyze the situation of children.

From the Congress, positions of governments indicating the cultural perception of children were classified from 1909 to 1984. The first 20 years of the Congress, from 1916 to 1935, was a period in which the congresses were classified as concerned about "the impure child". Documents disclosed perceptions about the immense majority of children populating America: children of mixed blood, blacks, mulattos and children of poor immigrants arriving from southern Europe. These children, who were illiterate, made up 50 per cent of the population. A congressman in 1924 said, "They have only a very fine veneer of civilization and have

no notion of their duties as human beings". There were calls to diminish the gap between these real children and the children dreamed of as the start of a new, healthy and strong race. Eugenics and the law were selected to dissipate the dark threat to the race.

Immigrants were selected as the founders of this new race because people such as the French ambassador, Joseph Arthur Debogino Conde, of Brazil, an influential figure in the most conservative European positivist movement, believed that the non-European races lacked the necessary biological basis to become civilized. A vigorous investigation of heredity was needed to correct the anomalies of that "inferior race". The American child should be robust, strong and virile. Not one congress at that time made any reference to the structural causes of poverty. During that period, the patriarchal provider state appeared and with it the protected and repressed child.

During a second stage, from 1942 to 1968, the dangerous young child was identified. This came at the end of the Second World War, when the voices appealing for the improvement of the species were quiet, and new voices were raised out of concerns for the safety and stability of the new society. It is important to remember that, in spite of current difficulties, the post war decades in Latin America were periods of hope for the future. Latin America moved towards establishing its modern industrial agricultural infrastructure. At the same time, however, there was no corresponding development in political and economic spheres. The participants of the congress themselves recognized that the Latin American indigenous world was not present in the national life of their countries.

This brings us to the latest congresses from 1973 to 1984, excluding the 1993 congress entitled, "The child that cares for himself: The children of the street". The study of American perceptions shows that, in Latin America today, elements of the pre-Colombian period coexist with elements of the modern period.

Feudal regimes exist alongside modern regimes. The 1959 *Declaration of the Rights of the Child*, the World Summit for Children, the World Plan of Action for Children, the national plans and the legislative measures will not be applied in an empty context.

The *Convention on the Rights of the Child* raises concerns about Latin America law and practice. Intellectual and cultural development in Latin America generated an enormous number of laws. It is a region with a great legal tradition, borrowing from Spain, Italy, France and Germany. This tradition culminated in today's "tutelar right of minors". As indicated by its name, this law or system is based on a series of legal fictions. It is the only Latin American law where the judge is not a judge but a substitute for any lack in the family, the community or the state. It acts as a *bonus pater familiae*, providing decisions in non-jurisdictional emergencies and in social and economic issues. This law is based on the fiction of the old *patria potestas* of the Roman system: the elder man in the home, a citizen, with patrimony. He is an owner of lives and deaths of the members of his family. Although more moderate now, it is still present in the authoritarian structure of the Latin American family. This law is also based on the legal fiction that the minor is non-imputable.

The intention of the law was worthwhile: to separate children from adult penal law. In practice, it resulted in just the opposite and created a perverse system in which there are no requirements of due process. In other words, a child can lose his or her freedom on the basis of a judge's decision without a court ruling or the presence of counsel. This does not happen to the worst adult offender.

The *UN Convention* states the new doctrine of integral protection, based on the best interest of the child. This is an undetermined legal concept, and we have much to do in the elaboration of these tenets from a legal perspective. Until that is done, the interests of the child will be determined by this *pater familiae*, be it guardian, judge, parent, teacher or adult. The *Convention* also states that the child is to be recognized as a subject with all rights. This is the paradigm, and the most important idea to come out of the *Convention*. It creates the possibility of a new culture that questions the roots and principles of power in a politically organized society. It questions power in relations between different persons, some of whom up to now were considered persons in situations of inferiority to others, such as women to men or vice versa, minority ethnic groups to certain other groups, students to teachers, and children and youth with disabilities to "normal" children and youth. In reality, it is the exercise of a non-authoritarian culture.

This is the paradigm the *Convention* represents to Latin America. Three years ago, in Honduras, in a very beautiful town called Valle de Angeles, known for its traditional wooden handicrafts, there was a small 10-year-old child. He looked as though he were only three years old, however, and he worked carrying wood from the mountains to sell in the Valle de Angeles. Ironically, his name was Angel. Although that is not life for all Latin American children, it is life for 120 million children. While children continue to live like this, compliance with the *Convention on the Rights of the Child* is still a very distant hope.

CHAPTER 3.

Fighting for Our Rights

BY HUMBERTO JORDANO QUINTERO, NICARAGUA

My name is Humberto Jordano Quintero. I am 20 years old. I have a large family because we are seven siblings, my father and my mother. In my family there are three siblings with problems of intellectual disability: Leonardo, 21 years old; Urania, seven years old; and me. Currently, we live in the city of Managua, which is the capital of my country, in a neighbourhood with more than 2,000 people. People living in our neighbourhood are mostly low-income people.

The street where my house is located is a large avenue, where many cars and buses go by. Six people live in our house. Relationships within my family are quite good. They help me with any difficulties I might have, they support me to some extent, so that I may develop myself and perhaps, in the future, have less difficulties. I get along well with my siblings and especially with those who are like me.

My mother noticed my problem when I began my preschool studies, since I did not assimilate well what our teacher was explaining, and she told my mother that I should have an assessment, after which they realized I had intellectual disability problems. Due to this problem I was registered in a special education school where I completed my elementary schooling with some difficulties in mathematics and Spanish.

My parents used to explain to me at all times that I was not like everybody else, that perhaps I could not go to the same schools all other young people of my age attended. They were afraid of secondary school because it was harder. However, I have insisted on registering and continuing my studies in a general institute, as I feel that I am able to continue and I want to prove to myself and to my parents that I am able to do it.

The fact that my mother is in the association of parents with children who have disabilities, Los Pipitos, has allowed me and my siblings to overcome many insecurities and to realize that we are able to do many things that are important in life. For instance, my brother Leonardo and I are members of the swimming team of my country that participated in the first Olympic games for people with disabilities, which took place in Madrid, Spain, in 1992.

Currently, I am attending the second grade of the evening shift of a secondary school. During the day, I work at the Institute of Social Welfare's training centre for people with disabilities, where I earn a minimum salary of 200 córdobas a month, equivalent to 25 dollars.

I am also attending carpentry and computer science classes. It was not that easy for me to get a computer science teacher to accept me in his group, because he thought that I was not capable of understanding anything. He told me that he will not give me a certificate. That made me feel badly. At the beginning I thought of dropping out, but after talking with an advisor at Los Pipitos I decided to accept it even if it was just to practice at Los Pipitos to demonstrate to the teacher and to myself that I was really able to understand computer science.

My brother and I are members of the Los Pipitos Swimming Club, where we have the opportunity to compete with other swimming clubs of non-disabled young persons. This has been useful for helping those young persons and the public attending those events to realize that we, the same as all other young people, have the right to be included and that we are capable of doing many other things.

I have many friends and I get along very well with them. When we are at school they help me to solve problems I may have in some subjects and we meet to carry out several activities such us study circles. When there are parties, we go all together to dance, boys and girls. They respect me the way I am and also respect my ideas.

I like girls very much and I have had crushes with some of them, but when they notice my mental limitations, they reject me, without understanding that my heart has no limitations.

I like to go to amusements parks and on outings. I also like nature, plants, trees and flowers. I like to watch television where there are many action movies. That is to say that the things I like are the same as yours.

I feel badly when there are arguments at home, especially when my parents scold me unfairly, because our parents try to impose their criteria on us without taking into consideration our opinions. I think that, above all, young people like me who have some limitations must struggle to achieve a better future, even if they have a disability. Like all other people, we will be able to do it if we make up our minds. I also feel responsible for my other two siblings, for helping them to have a better standard of living and to live in harmony. My big dream is to be able to go to a university and to have a career. I trust that society will allow me — the same society that speaks so much about human rights.

I think that, the same as us, all the people with disabilities in the world and in my country have a great task ahead of us: to fight for our rights, to be respected as we are, and to get support from all the other people ...

To finish, I wish to tell you with all my heart that when these meetings take place I am very glad, especially because we are working on behalf of our rights. For me, for my brothers and sisters of Nicaragua and of the world, there is *not a nicer moment* than when we feel that we are treated and respected as a person.

RASHAAD

BY ZUHY SAYEED

It was with much trepidation that we went to the elementary school for parent-teacher interviews. Our past experiences with Rashaad's interviews were those of frustration. Interview day for Rashaad always seemed to be more of a formality than anything else. To spend 15 or 20 minutes discussing his grades as compared to the rest of the class and hearing the inevitable "needs improvement" was something we really didn't want to deal with. Nevertheless, we walked into his classroom at the appointed time ...

Seated around the table were Rashaad's classroom teacher, his special education coordinator and a student teacher. We exchanged pleasantries and before I could say a word, his teacher spoke. "The first thing I want to tell you," he said, "is how much I have learned by Rashaad being in my class." He pointed to the wall behind us. "In fact," he said, "I now have a sign up there. I only wish all my students would realize how much they have learned." We turned around. The sign on the wall read: "The only handicap is a bad attitude." Tears filled my eyes as we just looked, stunned, at the teacher. He went on to tell us how amazed and impressed they all were by the sheer determination and motivation Rashaad displays and how willing he is to try everything.

You could have knocked us over with a feather. Never had we held a meeting where teachers and other professionals had not laboriously pointed out areas and skills that Rashaad "needed to work on" even though we have always explained the neurological obstacles in his way.

The interview was like a breath of fresh air. It was, for me, a feeling of elation, of finally being understood and on side together. It was a feeling of true support for the young persons we were all there for — and a sense of real accomplishment.

SECTION II.

PARTNERSHIPS IN COMMUNITY LIVING:

Strengthening Family through Policy Initiatives

In our complex, ever-changing society, all families face constant challenges. These challenges are even more difficult for families with a child who has a disability. This section provides an international perspective of families with a member who has a disability. It focuses on families' needs in order that they can enable the equal recognition of their children's human rights.

CHAPTER 4.

Stronger Families — Stronger Society

BY ROBERTO LEAL OCAMPO, NICARAGUA

It would be easy to praise the virtues of family and community life. It would be easy to point out that when there is harmony in the family, human existence and the community are enhanced. It would be easy to be tempted by demagogy and to resort to endless clichés with regard to the family. But these clichés would only be simple and trite phrases.

I feel an ethical duty to address other matters related to the theme of the family: values, rules of social conduct and coexistence which today tend to run counter to the very essence of the concept of "family". I know in advance that I will touch upon sensitive issues and raise unpopular points of view but I believe firmly that I cannot avoid these issues.

Without a doubt, the Americas are going through critical times economically, socially and politically. But we cannot and should not focus only on the economical, social and political aspects of this crisis. Profound and rapid change is occurring at home and abroad, exceeding the capacity of social groups and individuals to adapt. Women, youth and children are the most vulnerable sectors of the population. This process of rapid change has a dangerous effect — an effect that, as it becomes more dangerous, is more likely to go unnoticed: this process of change tempts us, human beings, to lose our capacity to be shocked.

So many disturbing things have happened and continue to happen that anything seems possible. Nothing shocks us anymore. We hear, for example, that the Bosnians and Serbs are killing each other in central Europe and that in Rwanda, in a matter of days, more than one quarter of a million human beings have been killed. We hear that in Nicaragua 70 per cent of the population is unemployed and that people live in hopelessness in Haiti. But we limit ourselves to thinking about them as "those poor people" and we remain detached from the affairs of others who seem far away from us.

Anything that happens beyond our immediate surroundings, no matter how strange, dramatic or painful, seems normal to us. Unless these events touch us directly, nothing shocks us. In a parallel way we, therefore, end up *allowing ourselves to be defeated by scepticism, indifference and apathy.* These three so-called values are a menace to all the Americas, particularly to American youth and to the millions of families who allow themselves to be defeated by hopelessness. A society based on apathy, indifference and scepticism benefits few people.

- When a community is based on indifference, its members will not develop solidarity or work together.
- An apathetic society will not find any reason to fight in unity for its legitimate rights and will abandon its principles. It will go quietly like a lamb to slaughter.
- A sceptical people will not hear those who call on them, regardless of whether those calling are right or wrong. They will make no effort to analyze a situation or arrive at their own conclusions about a situation.
- People who are apathetic, indifferent and sceptical will lack constructive goals with respect to their own future and the future of the community to which they belong.

A generation of people such as those described above prefers to be distracted by the passions of the current soap opera rather than taking care of the issues in people's daily lives. The people prefer to detach themselves from reality by crying with the main character's misery rather than being interested in the problems of their neighbors, although their neighbours' crises are usually more dramatic, and closer to their own problems. Such a community ends up insensible, like the three monkeys who refuse to see, hear and speak.

If we allow ourselves not to be shocked, if we allow ourselves to be embraced by indifference and apathy and if we allow ourselves to be consumed by scepticism, we will be giving up the basic characteristics that distinguish human beings from beasts: *the capacity for criticism and creativity* — the characteristics that have led the human race to pre-eminence on the planet.

Today's nations are confronted with a new world in a state of permanent metamorphosis, not only in the economic, social and political spheres but also with respect to values. This violent change generates, as a byproduct, a situation of *uncertainty*, even of *anomia*, in which individuals find that their frame of reference has changed and that they are in a society where the rules are radically different and unknown.

Although it is difficult to admit, in our changing world we are witnesses and victims of a duality, a confusing double morality. On one hand, we hear appealing words about peace and love. On the other hand, we are witnesses to relationships between human beings that are an absolute negation of the peace and love that is preached. We perceive the gap between actions and words. As a result, many people conclude that life consists of deeds and actions. They prefer to follow role models rather than heed words. In addition, although we are told daily about liberty and democracy, in practice we are less free and more enslaved by

materialistic desires. Authentic democracy is practiced less and less because we have less access to the arena where decisions are made. At the same time, the reign of the free market and competition reaffirm and consolidate new social rules in which the law of the strongest prevails and the power of money — not the power of reason — is upheld.

In the context of today's values, the honest citizen who acts according to ethical and moral standards is labelled "naive". In the meantime, the corrupt and unscrupulous individuals, the ones capable of doing anything to further their objectives, receive approval and acclaim, allowing them to succeed in life.

Today, change comes so quickly and is so profound that honesty, loyalty, fraternity and solidarity have become, for many, out of date, obsolete and archaic. They have been replaced by insincerity, betrayal, falseness, egoism and hypocrisy as valid, natural norms of conduct.

Youth and adults are offered a "paradise" overflowing with consumer goods, full of light and colour on the surface, but corrupt at the core. We are all offered a garden of Eden, promoted through modern marketing where corruption is imposed and where anything is valid, including mutual annihilation. We experience change that promotes evil values, destroys ethics and distorts morality, making the rich richer and the poor poorer and perpetuating injustices, such as injustices reported by Latin American Catholic bishops at Puebla, Medellin and Santo Domingo.

Our society, teeming with difficulties, can cause disaffection. In face of these uncertain times, there are many who have taken refuge in fierce individualism, responding only to their own basic and immediate needs. It is easy to fall prey to indolence and apathy. Everything contributes to making each citizen an isolated being who tends to submit to pure selfish individualism, piting him against all those around him. Day by day, *individualism acquires new adherents*.

The renunciation of romanticism is another consequence. "One does not have to be romantic" it is often heard these days, which discounts noble and altruistic attitudes. The death of romanticism is proclaimed throughout society. This opens doors to vices and new rules of the game that slip in unobserved and subject us to brutal rules of the jungle. Beneath the intention to bury romanticism lies the veiled intention to renounce dreams, to renounce visions of utopia we sometimes allow to blossom, brimming with life, like a Christmas star guiding us along the road of life. Living to build a beautiful dream gives purpose to one's existence. People's sacrifices, efforts and unselfishness go into building utopia — a society in which social justice can be a daily fact of existence, a nation in which the common good is realized daily and a person can be a partner and not a wolf at the door. Today it is considered "romantic" to try to carry out the imperative, proclaimed two thousand years ago, to love one another.

Today the cynic has replaced the romantic and cynicism rules. Everything has its price; everything has a monetary value. The worship of superficiality, frivolity and appearance grows daily and is more dangerous for humankind than the destruction of the ozone layer. The idea that modern man and woman have more value because of what they possess than because of what they are has been promoted. People are led to believe that success and happiness are closely connected. Even more, they are encouraged to believe that they must rely on material possessions and in their efforts to acquire these possessions any action is valid.

But we are convinced that our countries cannot abandon their dreams because if there are no dreams, if there is no utopian vision, life itself becomes monotonous and meaningless. There is no incentive to build something worthwhile and enjoyable to leave to future generations.

If there are no dreams, what is the struggle for? If human beings lose hope, we will fall. Our souls will collapse morally and we will

drift without initiative. We will not have the incentive to begin the struggle to build our own and our family's futures. Joan Manuel Serrat, a well-known Catalan singer-composer, sings:

> *Because without dreams, without utopias, life is only a slow and boring waiting room for death.*

Obviously, our societies deserve a better fate. Without a doubt, working to create new horizons is a moral imperative if the commandment to love one another is to be realized. We have to be willing to assume this commitment.

I am aware that these words seem reflective of a pessimistic attitude, addressing discouraging matters. I want to explain myself to avoid any misunderstandings: I am firmly convinced that the major problem of the 20th century is *the loss of values*. I also believe that this is an unknown phenomenon hidden in the vicissitudes of daily life. Material needs, by their nature, are like a gigantic smoke screen that prevents us from appreciating the magnitude of this problem. Finally, I also believe that authentic human values, those that should be common to the behaviour of men, women and young people and not an exception to the rule, are born, grow, develop and multiply in the family. Therefore, it is in the family, in that basic unit of our society where one can withstand those new and dangerous winds, that these forces can be overcome.

The challenge is a serious one. Defeat would bring our society to the verge of collapse. The family, therefore, is the first line of defence. We have to understand this and to regard family as the first line of battle in the struggle and also as the most vulnerable point of attack.

The concept of family and its daily interactions have not been immune to attack. It is common to see fathers against mothers, children against their parents, brothers against brothers. The family is disintegrating and its demise will affect us all.

Consequently, one of our basic and immediate objectives should be to strengthen the family. Strengthening the family implies strengthening the whole of society. As long as one can count on unified families based on solid principles, people will less easily fall prey to the corrupt "values" discussed earlier.

To strengthen the family means to struggle because love prevails over hatred, good over evil — not only in poetry or in a metaphorical sense. There are many examples in today's world of this struggle for values.

The family is an important source for the generation of positive values, attitudes and practices. Within the family the basic character of each individual is shaped. Within the family each person acquires the ethical and moral foundations that he or she brings to the difficulties and experiences of life. Human development begins in the family. A broken family hurts all its members. The disintegration of the family affects all of us.

Until now I have not mentioned disability. I have not done so because I firmly believe that the threat to our values affects us all and this includes, of course, people with disabilities. When one talks about the family, there is no reason to segregate people with disabilities. I am also certain that the disintegration of the family (as a consequence of the loss of values) affects all of us, including persons with a disability. How can we, for example, talk about the integration of individuals with a disability in a society of wolves and pirates? What kind of society and, therefore, what type of family can we offer to our children? When we talk about the family, we cannot restrict ourselves to families that have members with a disability. We have to focus more broadly and with a view to integration.

On the same note, as long as a family remains united, as long as its members remain bonded with fraternity and equality, each one of its members will have a better life. That includes people with disabilities. Moreover, children with disabilities, and

people with disabilities in general, usually find that their first and main source of support is the family.

- It is in the family that thousands of people with disabilities, and in particular youth and children, find a fertile environment to express the joy typical of youth. This environment is difficult to find elsewhere in a society led by "bored" adults, who usually repress and restrict this joy, sometimes in a desire to overprotect.
- It is in the family that a great number of persons with disabilities know one another and live in solidarity with each other, a situation that is not only seem negatively in a competitive society but also is difficult to find.
- It is in the family that thousands of people with disabilities channel their courage, allowing them to take on the challenges of life that give them pride. The larger society changes them and offers them a segregated and monotonous way of life.
- It is in the family that many people with disabilities find an environment that does not limit their creativity. There, they can be as inventive as they want to, without having their expressiveness controlled, as often happens in society at large.
- It is in the family that persons with disabilities often find a welcoming environment in which to rebel against a tired, dejected, distrustful, disillusioned world that is hostile to them and refuses to recognize their very human concerns.

If we are to build a better world for all, we must dedicate our efforts to building more solid, integrated and holistic families. If we do not carry out this task, we will soon pay the price of our negligence.

CHAPTER 5.

Social Policy and the Support of Families

BY AMINTA SPROCKEL, CURAÇAO

What do I think of when I hear someone mention a strong family? I think of a family in which the family members love each other, where they have high moral standards, where they try to remain positive in good and bad times and where they try to assist each other where they can. It is extremely important for a child with a disability to have a strong family, in which the family members love him or her and each other and try to help each other where they can. Acceptance of this child by family members is the first thing that must happen. The more complete the acceptance, the better the atmosphere of the family and the happier the person with a disability.

In what circumstances would this acceptance occur more smoothly? I think it would be difficult for a family to accept a child with a disability when the family members have problems themselves. Social, financial, emotional and other problems will make the acceptance difficult. The vision of life of the parents, which will determine their way of living, is also very important. How do they see life? Do they have certain religious convictions? Do they think positively or negatively? Do they have a social life? Do they have friends and acquaintances, on whom they count? These factors will influence the strength of the family.

Personally, I have had many blessings which have helped me build a strong family. Although I have had some severe blows in my life, I have survived and I am happy. I come from a family of 11 children, where my father had to work very hard to take care of us. He had a plantation. My older brothers and sisters began to work as soon as possible to help educate the younger ones. My mother was always in a good mood and had a great heart. Our family was educated in religious faith. I have pleasant memories of my youth. I am fanatical about my hobbies. I played for volleyball for 15 years with my heart and soul. I was the captain of the team, referee, editor of a volleyball magazine, player on the national team, coordinator of school competitions ... in one word: "fanatical".

Then I married and the birth of my first daughter, who has Down syndrome, brought a tremendous change in my life. I changed from being a fanatic sportswoman into being a dedicated mother and later a pioneer in the care of the people with intellectual disabilities. In my family everyone followed this change with great interest.

My daughter Josette, a very cute girl, was the doll of the family. My mother, sisters and brothers all tried to facilitate my caring for her. She is the one who inspired some of my relatives to choose a career in this field. Josette's sister is a speech therapist. Her cousin is the only sports and recreation therapist in Curaçao and director of the Curaçao Special Olympics. Another cousin is a teacher in an early stimulation program, while her brother is also studying sports and recreation therapy.

Similarly, with the parent's association, I tackled all my relatives to join efforts with me for the welfare of people like Josette. They helped with translation, fundraising, volunteering and selling tickets to events while Josette's sister and brother, although very young at the time, were involved in all our social events.

An important factor in my life with Josette was and is my faith in God. That too was given to me by my parents. All these things were positive factors which made my family strong.

I feel that one change in social policy important in helping families with a child with disability would be the implementation of the right to early stimulation. I would also advocate for the right to moral and financial support for families. In my opinion, parents of a child with a disability need support and guidance to educate this child. Such guidance should be directed not only to educational aspects, but also to emotional aspects. Families need to know where to go for help with social problems. I speak from my own experience as coordinator of the early stimulation program in Curaçao for 12 and a half years. This program involves more than teaching parents to stimulate their children. In my eyes, it is a philosophy. Because the child lives in a family, which is the smallest unit of the community, all family members — parents, brothers, sisters, grandparents, uncles and aunts — must have the same philosophy and approach towards their relative with a disability.

It is a real advantage to have a strong family and the time, attention, love and energy you invest in your children when they are young will pay off later a hundred-fold. The result is tremendous, as you will see by the story of Josette.

Josette, born 26 years ago with Down syndrome, was very high functioning. She went to the play-yard, at first alone, then with her younger sister. At five years of age she went to a regular kindergarten and after that she visited a special school for "children with severe retardation". When I saw, after four years, that she could do more than the average child at the school, I had her tested and was advised to place her at a school for "children with moderate retardation". This school had never had a child with Down syndrome, so I had to fight hard to get her there. She did very well and after four years she finished at that school at age 15.

Upon leaving the school she had the right to be placed at the school for girls — in home economics. Again I had to launch a fight to place her there and, at the age of 19, she was ready to leave the school.

I found her a job in the laundry of the maternity home where she was born. She was very happy there, sorting and folding clothes and doing other tasks when, after four months, things began to change. She become depressed and quiet. She lost her appetite. I took her for a check-up and went to great lengths to find out what was happening. After five months it was discovered that her thyroid was not functioning well. She was prescribed medicine—Eltroxin—and I was told by the specialist that everything would be fine. But now after six years I have to say that her level of functioning has declined. The worst decline happened two years ago, when she began to lose her ability to understand concepts. They call it "aphasia". Communication became very difficult which, for me, was terrible. And then something happened that I had never experienced when she was a child: she withdrew emotionally. Because Josette and I were alone at home — her sister was studying in Holland and her brother was in the United States — this setback was hard to overcome. However, my family, friends and colleagues supported me wonderfully.

I began to write poems during my sleepless nights and called friends when I needed to talk. In the meantime my second daughter finished her studies and is back home and supporting me. My son is now into his third year of college. When he is with us during vacation he is the ideal caretaker of Josette. He is the one who convinced me to let Josette do things at her own pace. I was rushing her too much, frustrating her. It took me a long time to adapt to Josette's way of doing things but it works for all of us because the atmosphere is relaxed and happy.

Josette was very good at reciting poems and on several occasions she performed as a real artist. Josette recited a poem about a girl with Down syndrome pleading her mother not to cry, not to be ashamed of her — which occurs when someone is still struggling with acceptance. That poem inspired me to write an answer and express the feelings of a mother who found strength in positive circumstances and her faith in God.

O Mother

Do not curse the hour of my birth,
because all I have, I have from you.
My colour, my hair.
O stop, do not cry any more.
Sing a song for me.

That song from the time we were one,
From the time I was beneath your heart
Or have you forgotten it?
Ask Father, he does remember.
For tears there is enough time.

Let's go out
so I can enjoy the warm sun.
Show me the birds and the goats.
O, do not look in pity at me,
when you see other children play.
And do not be ashamed, when we have visitors.

Pray for my soul, because I cannot do it myself.
Who knows how beautiful your child's life will be,
after this one.
Our sorrow will be short,
O do not cry,
sing a song for me mother.

Jubilation for Josette

My heart sang out in jubilation,
the moment you were born
and I was enchanted
by your body, your face,
your lovely hair.
Never had I known greater pride,
than when, through you,
I had become a Mother.

Later,
after my acceptance
of the shattering knowledge
that you were different,
my heart once more knew jubilation,
for you filled me with inspiration
to reach for a higher goal in life,
proving to others
the beauty of the lives
led by people like you,
my love.

I sang to you and for you
all the songs I knew.
We shared the joy of birds,
goats, the sea,
and the sun that rises
for us all.
Your doting siblings played with you
from early morn to dusk.

And my heart would not have ceased
its jubilation ...
But then, Nature, who had played
at hide and seek with us for years,
suddenly sprinted past me
and turned out to be the winner
after all ...

Nature cruelly took away
the credits of my efforts;
chased away my expectations.
There I was: a child
who had lost her favourite doll,
crying, crying ...

And then I made a choice:
instead of shedding useless tears,
I would, through continuous jubilation,
express my gratitude
that you made me see and understand
the grief that weighed
upon the hearts of my fellowmen.

I thank you for lighting *my* heart
by teaching me
to more profoundly appreciate
the moments of sheer happiness
of yesteryear
and of the present
that is left to us.

Now I pray that I may obtain
a portion of your innocence,
so that I may, some day,
meet with you
in the presence of the Lord,
to then raise our voices
and our souls unto Him
in eternal jubilation.

Aminta Sprockel, 1993

CHAPTER 6.

Challenging the System: The Parent's Struggle

BY PAULETTE BERTHIAUME, CANADA

Many times over the past few years I have listened to a very powerful French song about war and liberty. The singer is Juliette Greco. It is called Chante, mon fils, chante, which means "Sing, my son, sing". She sings about her son who is at war and she sings about liberty and freedom. Why is this song so powerful to me? I remember when I listened to it for the first time on the radio the image of my son came flashing in front of my eyes. My son Louis, a handsome man of 40 years old, is a free man today. He has been out of the institution, where he lived for 32 years, since the first of April, 1994. It was the most beautiful Good Friday. That same day, I was a free woman. A part of me had always been there with him, "inside". I used the word "inside" for a reason; to me the institution was a prison. I always felt that my son was at war trying to survive. This song helped me to fight for him.

We are a small group of parents trying to force the government to integrate 91 persons — our sons and daughters who live in that institution. Our sons and daughters are vulnerable "inside". They have no voice. We are the eyes of our sons and daughters.

It became urgent to take my son out as soon as possible because he had begun to mutilate his wrist. I decided to put all my energies into his integration. I argued with government department after government department. It was a time full of hardship but we made it. It was a beautiful victory. I have taken my son out alone, but we are hoping that the 90 others will join us in the community soon.

Over 30 years ago, we had no services for my son, no school for him. I could not accept having him at home. I went to the premier of my province but nothing was done. Louis was denied an education. It is a law that every child has to go to school until he or she is over 16 years old, but not Louis. I was brought up to believe in our laws. We believed in the institutional system years ago until some people in British Columbia showed us alternatives — a home for everyone.

The system keeps pouring money into institutions, into structures and professionals instead of closing institutions, so our sons and daughters can live like you and me in the community. The danger of institutions is that when a family has no services in the community, no one to turn to, the institution is there; it opens its doors. People with disabilities are treated as sick persons. How can the system permit our sons and daughters to remain in institutions all their lives? What have they done? If I was an offender, I would serve my term and out I would go. No one would keep me against my will.

Where are we today in society concerning our attitudes towards, and acceptance of, a person living with a disability? Have we changed that much since my son was born? Forty years ago when Louis, my second child, was born, I was the happiest person on this planet until the day when my son's pediatrician informed me of his intellectual disability. I did not know what he was talking about. My son was a healthy baby. The diagnosis was: he would never go to school, would never work and would

need supervision all his life. He warned me about society's attitude towards my son. At one point he decided to give me an example of what the life of Louis and my family would be. He said, "Let's say your oldest son breaks a window of your next door neighbour's house. What will happen? You will excuse your son, you will have to repair the window, pay for it and that will be the end of it. But if your son who has a disability breaks a window they will not excuse your son for this. The whole neighbourhood will be talking about it and watching all of his actions and worrying about his whereabouts." I could not believe it. Louis was a three-month-old baby.

Last year I was invited by an agency to help them convince the people living in a village of the benefits of building a house for a few people with multiple disabilities. It was a well-planned, attractive house. I was asked by the people of the village if the people living in the house would be able to walk. They did not want them wandering around, they said. The people in the neighbourhood had children they worried about. The house was eventually built but at what price?

The Stronger Children — Stronger Families conference is about fundamental rights: the right to live a decent life; the right for a child to have a family; the right to attend school; the right to work; the right to have leisure; the right to love; the right to make friends; the right to take risks and so on. In this country we have social policies, the *Canadian Charter of Rights*, the *Quebec Charter of Rights*, the *Livre vert*, the "green book" produced by the government of Quebec, saying that persons with a disability should not be discriminated against and should live in the community. When we look back, we can see that we have made progress, but we still have a long way to go. Many of our policies exist but are not implemented. Regardless of the laws and social policies, if there is no political will, nothing will happen.

As parents, we have always had to fight and we are still fighting for the rights of our sons and daughters. In many places in Canada, parents are struggling to integrate their child with a disability in a regular school with their friends. Some parents have taken legal procedings. The system is demanding of parents; it demands that they be supermen and women.

I often say that my son is part of a lost generation. Let's not produce another lost generation. The system is not working for the family. There is not enough help financially or otherwise. It is very hard for a family to adjust when a child that is different is born. To be together as a family they need to be helped, more so today because often both parents have careers and if all the services are not in place for their sons or daughters they will be a disrupted family. It is not easy for the child with special needs in our society today. We value only performance, competition and excellence. We, as parents, have to continue to stand up and be accountable so our sons and daughters can live a decent life. We should continue to challenge the system and support one another.

When you look at our sons and daughters, see a child, a man, a woman, not a handicap. Our sons and daughters are the same as all persons, with the same basic needs.

CHAPTER 7.

Creating a Vision: The Rights of Children in Jamaica

BY PAULETTE BROWN, JAMAICA

In Jamaica there are many policies that govern the right of the child and the family's obligation to carry out those rights. Jamaica has ratified the *UN Convention on the Rights of the Child*. Our major problem is in its implementation. They are many families with children with disabilities who are poor and have very basic education. Therefore, they are not aware of their rights or those of their children. In the organization in which I work, 3D Projects, the first thing we do is:

1. Mobilize parents.
2. Educate them about their children's disabilities and the rights of their child.
3. Give the parents support.
4. Assist with Income Generating Projects for them to become independent (as, in Jamaica, mothers are generally the sole bread winners).

Once they develop confidence, parents are more able to demand the rights for their children by advocating for the right of their children to go to schools along with other children, by

speaking with teachers about their children's needs, by writing to government ministers about food stamps and other programs and by lobbying for health care.

When they have more confidence, parents are also better able to understand and resolve conflicts in their families. Most families in Jamaica have problems with poverty, poor housing, overcrowding, unemployment, poor medical facilities and other social conditions. Families face hardships, frustrations and tension. Most families tend to be large in number. Conflicts arise because children do not understand parents and parents do not understand children. This can lead to child abuse, a lack of discipline in children and lack of acceptance of a child with a disability. To resolve these conflicts, we need to provide better income and better living conditions for our families. Once these are achieved the situation always changes and many of these conflicts begin to be resolved.

Interaction between parents and children begins with bonding, acceptance, special love, trust, play and listening. For example, in education, when dealing with a child who shows delays in her motor skills, the child will only be able to achieve if the family exercises great strength, as was my case. It was not hard for Shanique, my daughter, to be settled in the regular school system because long before she was ready for school I made plans for her education. I became acquainted with the principals and teachers of all schools in my area and made regular visits to those schools, helping with "devotion", lunches and tidying the classrooms. After Shanique was enrolled in a school for one year, I decided to enroll her older brother in one of those schools. All this was possible because the bonds had already been created. He was always ready to push her to school and pick her up in the evenings. At lunch time, he would help her with her lunch.

To strengthen families through policy initiatives, the family must play a role in deciding what those policies should be. So many times policies are made by persons who have no real experience of what it is like to bring up a child with disability. Therefore, although they may have all the goodwill in the world, they might create the wrong policies, because they have not discussed with, or found out from, persons who are involved with children with disabilities what their needs are. Therefore, instead of the policies strengthening the family they present an increased burden to the family. In order that families are strengthened by policy initiatives, families have to be involved from the start.

Shanique is my oldest child. She was born prematurely and at her birth I was told she would not live more than five days. She was born at a local hospital where the doctor was not Jamaican and I think he did not know much about our Jamaican situation. I was so shocked when I heard the doctor say that, I said to myself, "If Shanique will only live for five days they will have to be five very good days."

Shanique lived in the same hospital for one month and one week. One day I approached the doctor and said, "Doctor, I think it's time that I take my baby home from this hospital." He refused to discharge her. I was given a document stating that I wanted my daughter in my home and if anything should happen the police would investigate. I signed the document and took my daughter from the hospital.

Our custom in Jamaica is to give our children a lot of porridge so I began to give Shanique a lot of porridge. She was so small that it was hard for me to manage her. I didn't have a lot of parental support. My mother didn't know much about children with a disability. But I took it on myself to teach my family about children with a disability. I began with my husband, to tell him everything I knew about Shanique. Each night I would wake him up and I would tell him something about children with a disability.

I felt it was important for Shanique to have other family members around her. I had another baby but she died. So I took in other children who were close to me — some of them from my husband, some of them from my friends. I took them into my household. I want to tell you something about myself. I'm very determined. I take a lot of these things on myself and then I make a presentation to my husband. When I took in these children my intention was that Shanique would have these children to copy in order to learn the things she needed to grow. These children are from the age of 16 to Shanique's age. We are a very close family. If something hurts Shanique it hurts me. These children are all a part of her and plan for her each day. They keep her busy. Sometimes she is at parties, sometimes at church. She is always doing something. One of the bigger boys takes her to school. When she's home from school another brother takes her walking in the community. This is how Shanique's days are spent — happily. I'm able to travel all over the Caribbean because of these children. They take care of her. Shanique is now nine years old and she is functioning to the best of her abilities. She learned to walk three months ago and she can say what she wants to eat. She knows what she wants to wear. One thing I'm sure of is that if I ever pass away Shanique will have a family.

My job in Jamaica is very difficult because so many programs for children with a disability in Jamaica were started by people who don't know how it feels to have a child with a disability. But we are not governed by these rules and laws because so many times they are not what we want as parents for our children. My job is very difficult because I have to go into the community and try hard to educate other parents who do not have the opportunity to go out like myself and experience other communities. I have to keep pressing them and reassuring them that there are better ways we can do things and that we are not going to stoop to what people have made for us. *We* have to make plans for our children.

SECTION III.

CHILDREN WITH DISABILITIES IN THE LEGAL SYSTEM:

What Equality Means When Children Have Disabilities

What does equality under the law mean if you cannot read, cannot talk or cannot walk? Justice and due process have new meanings as children with disabilities challenge the limits of the legal system. This section looks at the successes, challenges, strategies and the process of creating legislative and policy change with, and on behalf of, children with disabilities in Canada. A central theme is what being heard means for these children. Issues of communication, competency and credibility are examined under a rights-based model.

CHAPTER 8

Access to Justice and Children with Disabilities

BY TANIS DOE, CANADA

When discussing children with disabilities and the legal system, we must realize that children are children first and they are part of that category for a definite period of time — usually from birth to 16 or 18 years of age. They are offered special protection under the law and under the *United Nations Convention on the Rights of the Child*. This protection is necessary because they are vulnerable to all kinds of abuse and exploitation.

Abuse occurs because children, in specific relationship to adults, have no power. Parents, educators and care-givers have an obligation to provide support, nurturance and love in an environment that also provides food, shelter, clothing and health. But not all children with disabilities are able to benefit from all those provisions because most children with disabilities are denied access to basic aspects of life. For children with disabilities, their experiences of "childhood" are eclipsed or masked by their experiences of "disability". Too often the child's identity and experiences of child-"ness" are subordinated to his or her diagnosis of disability. Children with disabilities often miss out on the benefit of being a child due to the medical and social stresses of having a disability. The child is often denied a childhood.

One of the most serious problems connected with having a disability in childhood is the exposure to violence. We know that all children are vulnerable to violence because they have a relationship of powerlessness to adults. We know that children with disabilities are at particular and increased risk because of their disability. Because we know that there is intentional abuse of children with disabilties, it is important to realize that children with disabilities must have more access to justice, not less. We know that car accidents and illness deny many children their innocence and safety, affecting their lives on a daily basis, and often these tragedies are not preventable. However, child abuse is. And it is something that society has to confront. It is a social and community tragedy when the care-givers, family members and professionals are the offenders who are hurting children.

Children with disabilities, particulary those with severe and multiple disabilities, are at an increased risk of abuse and violence and yet they are the least likely to have access to the justice system. Bill C-15 has provided a window of hope to all victims of violence. It recognizes that children can and do tell the truth, can testify in court, and can and do understand the seriousness of promising to tell the truth. Prior to this legislation children had been considered not credible — at best. Adults with disabilities were treated the same as children. They had no credibility and were not allowed to testify. Changes in the law have allowed testimony to be given without taking an oath. Instead children are allowed to be asked if they understand what it means to promise to tell the truth. They are also allowed to testify behind screens or on videotape or closed-circuit television to avoid having to look at the offender. We know that this system is providing children with more access to justice because they are able to testify without having to face the person who, on a daily basis, had a position of power.

Yet we have a long way to go in extending to the children who are victims the human rights we offer to defendants. Children with disabilities, especially those who cannot talk, are not being given full access to this potential protection. Children with disabilities can be considered "prosecution-proof" victims. That means the offender can be almost guaranteed that there will be no prosecution or punishment because the child cannot communicate what happened, cannot name the offender, cannot describe the situation and may never have access to justice, all because of communication gaps between them and the legal system. As our justice system becomes better and better for non-disabled children, offenders will have to think twice before they abuse able-bodied children, knowing there is punishment for abuse. But for children with disabilities who cannot communicate there is almost no punishment and that means the offender will be able to take more advantage of these children, not instead of other children but as well as other children.

The court has discretion. It can ask: Can the child understand what it means to swear an oath? Can the child understand what it means to promise to tell the truth? Can the child communicate? All these things are based on criteria set by "the law" — law written by able-bodied white men who can hear and who can communicate. That standard is almost impossible to attain for children who have severe disabilities including autism, intellectual disability and hearing and visual impairments.

Many of these children are exposed to a variety of exploitive situations in the family and in institutions, group homes and medical services. Because of their dependency on care-givers to assist them in communication, because they are denied access to direct communication, because they cannot communicate in traditional ways, they are also denied access to justice. An intelligent, articulate eight-year-old girl who is abused by her stepfather will have a very hard time testifying in court perhaps

eight months after the abuse has stopped, even if the abuse was repeated and violent. Time passes. Memories sometimes change to protect oneself from pain. That child may be given all the supports available in the court system and still not be able to provide proper testimony to convict the offender. And that is an intelligent, articulate eight-year-old child. If you take a 12-year-old child in the same situation who is non-verbal, cannot use her hands and cannot use Bliss symbols, who has experienced violence and abuse, Crown counsel will almost certainly not press charges. Instead the child might be removed and put in another situation where she might again be exposed to abuse. We know that we cannot guarantee defendants' rights if we do not have communication. One of the basic tenets of the law is that you have to identify the offender. But if the child cannot communicate in a way that the courts recognize then that child cannot have justice and the defendant cannot have a fair trial.

We know that the law is only part of the process in stopping abuse but it is an important part in ensuring that we, as a society, tell offenders that it is wrong to hurt children and that it is a serious offence to hurt children who are in positions of dependency. Children with disabilities spend their whole lives in positions of powerlessness and the justice system reinforces their powerlessness by saying "you cannot participate". Because offenders are not being prosecuted and punished and because children with disabilities continue to be abused on a regular basis, we will not be able to track any improvement in the system unless we change the system.

One of the most important steps to improvement is to ensure that we have safeguards and third party involvement so children with disabilities are not isolated with care-givers. A problem I have seen in institutions is that people who are being paid to take care of children are often the offenders as well. If the child only has access to that paid care-giver, the information about the offence will never get outside the system.

A case in point is the deaf schools. For many years, deaf children were abused in the residential school system. Of course, deaf children are also abused at home, in their communities and by strangers. However, the educational purpose of the residential setting meant that a large number of deaf children were brought together in relative isolation from people who could not communicate with them and who might not have been able to provide them with an adequate education. Therefore, one of the benefits of having the deaf schools is that the children can freely communicate with their peers, developing a true identity with other children. But it also means that the only people who have access to deaf children are other people who sign. That means anyone in a position of power who knows sign language will have access to those children but those children will not have access to the public. This includes parents. Parents of deaf children often do not sign and they rely on paid care-givers to tell them how their child is doing.

As we know from experience, some of these children have learned that abuse is part of the normal process as they grow up. Then they too become offenders — deaf children tend to abuse other deaf children. Therefore, in the deaf community there is a cycle of violence that has stayed within the deaf community because there is no way to tell people who don't sign what is happening to them. The situation is similar in any other institution. This is one of the strongest arguments against isolation and segregation because isolation increases the risk of abuse.

We must stop the cycle of violence and this can only happen through systemic change. The courts are not the only answer. They are part of the process to address the significant inequalities and inaccessibilities of the system. If offenders are not punished by the system and not stopped by education, safeguarding and protection, children with disabilities will continue to be abused and denied access to the basic justice others take for granted. The

UN Convention on the Rights of the Child must apply to all children. The *Canadian Charter of Rights and Freedoms must* guarantee access for children with communication disabilities, intellectual disabilities and multiple disabilities. I do believe we can change, we can make a difference together — by challenging the status quo and changing it.

The following quote is from a book by the DisAbled Women's Network Canada, called *Meeting Our Needs*:

> *It somehow seems more okay to abuse an imperfect child, or someone who really doesn't know what is going on, or is powerless. Disabled children are powerless in many respects — if they can't move, they can't talk. If they can't hear, then it's a big surprise. I hate surprises now because if my father would come into my room, I wouldn't know it until he touched me. PHAAA! You know. It would always come as a shock. So my hearing impairment certainly made it easier because I could be snuck up on. Or they knew that when you are hearing impaired and don't know what is going on, you get confused. You get confused about a lot of things. You hear something and you don't really know what he said, until he's touched you. But until that point, I was not always sure what was going to on. It was always kind of confusing for me, frustrating. If they whispered — your awarness of what is going on is that much slower. Reaction time is slower. The reactions I did give were obviously ignored, when I did say no. I said no many times, I've discovered. I really did. I was always saying no, but it didn't seem to matter. No meant yes.*[1]

Children at any age, with or without disabilities, should never be expected to say "yes", to say "no", or to have to face sexual or physical abuse from care-givers. Because children do face this abuse, far too often we need to protect them by insuring that, whether they can talk, sign, gesture or not, they will have access to justice and protection offered by the law. Systemic change is necessary to ensure that violation and victimization of children with disabilities are not seen as "prosecution-proof" crimes and that survivors of abuse have access to the full range of options in their recovery, including the courts if they so choose.

NOTES

1. Shirley Masuda and Jillian Ridington, *Meeting Our Needs: An Access Manual for Transition Houses*, Toronto: DisAbled Women's Network Canada (DAWN Canada), June 1990.

CHAPTER 9

The United Nations Convention on the Rights of the Child: A Tool for Advocacy

BY DIANE RICHLER, CANADA

One of the questions examined at the Stronger Children — Stronger Families conference was: how we can implement the *United Nations Convention on the Rights of the Child?* Copies of the first report from the government of Canada on the *Convention on the Rights of the Child* were available at the conference. Every country that is a signatory to the *UN Convention* must prepare a similar report to the United Nations detailing its progress towards implementing the articles of the *Convention*. In Canada, because of the division of responsibilities for children between federal and provincial/territorial governments, a component of this document is written by the federal government and components are written by each of the provincial and territorial governments.

An official government document stating its position in relation to the rights of children provides a very useful tool to people advocating for children who have a disability. It is interesting to draw a comparison between the description contained in the official Canadian government report and the reality experienced by the Canadian Association for Community Living. These two are not necessarily congruent.

Canadians are proud of the fact that our constitution includes a *Charter of Rights and Freedoms* guaranteeing equality and specifically prohibiting discrimination on the basis of mental or physical disability. The Canadian report to the UN refers to the *Charter* in its opening pages as a basis for many of the rights of children in Canada.

To people who have a disability and their families and friends this means, in essence, that children who have a disability should be able to grow up with the same opportunities and to expect the same kinds of outcomes in their lives as do adults who do not have a disability. To the Canadian Association for Community Living, it means children with disabilities should enjoy such basics as growing up as part of a family, going to the neighbourhood school, being in a regular class with peers who do not have a disability, having friends, going to birthday parties and having sleepovers. It means preparing for a career to earn a living and preparing to have one's own home as an adult. But although those expectations, within the Canadian context, seem to describe an ordinary life, too often for children who have a disability and their families, conflicts with other pieces of legislation prevent that reality from being possible.

The Canadian Association for Community Living has been involved in particular legal cases and other situations dealing with issues that face children. Those same issues are included in the *Convention on the Rights of the Child*. It is instructive to reflect on what we have learned from those cases and to examine whether the *UN Convention* offers an additional tool for advocacy and for advancing the rights of children with a disability.

Traditionally, Canadians have not turned to the courts to deal with social issues, whereas this is a common practice in the United States. Many people believed that the entrenchment of the equality rights provisions within the Canadian constitution would provide a new tool to protect the rights of children with a

disability. In fact, since the equality provisions came into effect in 1985, some of our attempts to use the courts or to use the legal system more broadly to that end have taken us a step forward. Some have helped us to hold our ground; some may have taken us a step back.

One such situation took place five years ago in one of the most prestigious hospitals in Canada — a hospital affiliated with one of Canada's most renowned medical schools. A child was born with Down syndrome. The child had a blockage in the intestine that prevented him from being able to digest food. He required surgery to correct the digestive tract in order to survive. A decision was made, we believe on the basis that the child had Down syndrome, that the surgery would not be performed. The child was put in a corridor with a sign on the incubator saying "Nothing by mouth", and after 11 days the child, who has become known as Baby Dan, died of starvation. This happened in a province and in a country that has child protection legislation; in a province that has a provincial government organization responsible for protecting the rights of children when the people ordinarily responsible for that child are suspected of denying those rights; in a province with a human rights commission; in a country with a charter of human rights and freedoms. What makes the story even more frightening is that somebody close to the situation saw what was happening and tried to ring alarm bells. This person tried to intervene using some of the existing mechanisms, calling the child protection organization and going to the powers that be to intervene on behalf of that child, but nothing was done.

The government of Canada recognizes, as is evident in the Canadian report on the *Convention on the Rights of the Child*, that situations exist in which it is necessary for the state to intervene, particularly where the exercise of *Charter* rights of parents would threaten the life of their child. A common example,

given in the report, is that it has been consistently held that freedom of religion of parents does not extend to denying their children necessary blood transfusions. That particular situation arises in the case of parents who, for religious reasons, will not allow their child to be given a transfusion. It is accepted practice in Canada for child protection authorities to be alerted, to intervene and to have temporary custody of the child, allowing the life-saving procedure to be carried out. The child is then returned to the family's care. In the case of Baby Dan, a child with Down syndrome, this process was not followed.

The provincial Human Rights Commission, after lengthy deliberations, examined the situation. They stated that, in fact, the situation was serious and that there had potentially been discrimination on the basis of disability. However, it stated, because the problem was so enormous, a solution would require an extensive review of all practices for the care of newborn children with disabilities in the province. Since the Commission could not afford such an elaborate review, nothing was done. It has now been five years since the Human Rights Commission decided that, although there was cause for concern about discrimination on the basis of disability, they did not have the resources to pursue the matter. Now, they are ready to close the file. This is what the right to life means for children who have a disability in Canada.

There was a more heartening case concerning the right to treatment of young children in British Columbia several years ago. In the case of Stephen Dawson,[1] the courts intervened and assured that a child who needed a shunt would receive it. This was despite his family's decision that it was in his best interests to be allowed to gradually die rather than live as an adult with a disability. But although we have that case on record as a court decision, last year a child in Ontario was denied life-saving surgery by a physician at another world-renowned medical institution for children because the child's IQ was five points too low.

Many people in Canada claim that access to education for children with a disability within the regular school system has improved tremendously in this country. In many communities that is true. The Canadian government report to the UN describes the education policy in New Brunswick. This is the only province where it is law that every child belongs in a regular class and that there have to be particular reasons why a child should receive supports in any other educational situation. Yet the report is remarkably silent on the situation in other provinces and territories. In other jurisdictions parents, at tremendous personal expense, have had to go to court to gain access to the regular school system for their child with a disability.

There was recently a major setback in the province of Québec where a court of appeal overturned the decision of a human rights tribunal. The court said that the law in the province of Québec does not require that a child be educated in a regular classroom. It went on to say that a provincial education law giving authority to professional educators to assess and prescribe appropriate supports for children should hold sway and would have more power than the *Charter* with respect to where a student should be educated.[2]

There have been similarly discouraging results in cases of sexual abuse. There was a situation a few years ago in which a perpetrator of abuse against a teenager confessed on a much-watched national television program. Yet charges were never laid because neither the police nor the crown prosecutor knew how to get from the teenager the testimony they thought they needed in order to convict someone who had confessed on national television.

Although there have been improvements to the *Evidence Act* in Canada, one remaining phrase of the *Act* is a particular issue for people who have an intellectual disability or any communication difficulty. It is no longer a requirement in Canada

to swear to tell the truth. One can now promise to tell the truth. However, there are people who are unable to communicate that they understand what a promise means, even though they may show that they have never fabricated a story and may very well be able to communicate things that happened to them. Because of this phrase, those people are still not entitled to give testimony in court. There are a few judges in Canada willing to look at creative ways of ensuring that people who have a disability have their day in court as victims, witnesses or people accused. But their numbers are all too small.

Another section of the Canadian report to the UN deals with cruel and unusual punishment. Specifically, Section 12 of the *Canadian Charter of Rights and Freedoms* provides that everyone has the right not to be subjected to cruel and unusual treatment or punishment. Yet, just recently, parents of children who were living in an institution in Nova Scotia found signs of abuse on their children. These parents had to go to extreme lengths to draw attention to the fact that someone needed to look into those allegations.

This leads into the issue of the child's right to grow up as part of a family. Many children in Canada do not live with their families because laws provide funding to support children as long as those children do not remain with their families. It is, therefore, possible for a family in crisis to get support for their child if that child goes to live with another family or in an institution. The laws will not, however, give support to that family to solve their own problems in their own homes.

A major — and positive — court decision in Canada was the case of Eve.[3] The Supreme Court of Canada, in a unanimous decision and influenced largely by a group of people who themselves had been labelled as having an intellectual disability, stated that in Canada a person wishing not to have children and be sterilized is free to make that decision. However, if a person is

not able to give informed consent and is not able to understand what the process of sterilization means, then no one, neither parent nor lawyer, doctor or judge, can make that decision for them. That is what advocates for persons who have a disability thought the Supreme Court decision meant. Unfortunately the reality is often not as clear cut. There are still pressures in Canada to sterilize people who have an intellectual disability while they are young, before they have access to the courts on their own.

This raises the issue of reproductive technology — a major concern in Canada. Legislation being developed is potentially a major threat to people with a disability. We have noticed patterns in laws. One piece of legislation may look innocuous. However, several pieces of legislation, when considered together, begin to have a negative impact. For example, there is concern in Canada that people who have knowingly done something to put themselves at risk should perhaps not be entitled to certain health and social service benefits (for example, smokers cost more to the health care system). There are signs in the Canadian legal system that people may be held responsible for certain actions. The state may not want to support certain people who made choices about being in certain situations. In its harshest light, this might be called blaming the victim.

A piece of immigration legislation — proposed but not passed — gives us a clue to legislators' thoughts: this proposed legislation said that a family member who had a disability entering Canada would never be eligible for any ordinary health and social services available in the country. It said the family would always be responsible. This meant that there was discrimination within the context of immigration. It also suggested to us that there are people considering whether only some people with a disability should have access to health and social service supports.

The immigration legislation was being developed at the same time that the Royal Commission on Reproductive Technology was at work. One of the issues before the commission on reproductive technology — and one of the issues discussed when abortion legislation was proposed in Canada a few years ago — was different guidelines for abortion in the case of a fetus with a disability. There was a suggestion that for ordinary pregnancies the medical profession would define a point at which life began, at which the fetus was viable outside the womb. An abortion could take place up until that point. That date, determined by medical professionals, would not be written into the law. However, in the case of disability that date would not hold, allowing abortions to be carried out later in a pregnancy. Faced with those two pieces of legislation, we began to fear that certain ideas were developing: if a parent knew they had an opportunity to have an abortion to prevent the birth of a child with a disability and did not take advantage of that opportunity, would they then be denied access to supports and services for that child? Would differential supports be given depending on whether parents had taken steps to prevent the birth of a child with a disability?

Canada has immigration legislation that, in effect, prohibits families from coming to Canada if they have a family member who has a disability. The latest information is that the government of Canada plans to quantify this restriction. If a child or an adult with a disability will cost the health and social services of Canada more than $25,000 over the first five years that they are in Canada, that family will either not be eligible to come to Canada or, as happens now, only the family members who do not have a disability would be welcome. They would have to find somewhere else for their family member with a disability.

A person from one of Canada's First Nations said that it takes more than one pole to hold up a teepee. We have learned that we must operate on many different fronts as an advocacy

organization in order to bring about changes to the laws that cause our problems. When the person who assaulted the young woman confessed on national television, l'Institut Roeher Institute and the Canadian Association for Community Living were contacted about the situation. We had an opportunity to work with the family, the office of the Attorney General and the police to develop a protocol that would assure due process in future situations involving persons who have difficulty with communication. L'Institut Roeher Institute developed training manuals for lawyers and judges, police, families and counsellors in order to provide the tools people need to support individuals when they come before the law.

Despite continuous work on these many fronts, there is still a long way to go. We continue to come in contact with systems that are not operating on a framework based on the *Charter* and that do not fundamentally believe in the equality of children who have a disability within their communities. However, in turning to the *Charter* and the *UN Convention* and other such documents we have ammunition for approaching the government and the public to change systems. We have a basis for working towards the rights of children with disabilities envisioned in the *United Nations Convention on the Rights of the Child.*

NOTES

1. *Re S.D.*, [1983] 3 W.W.R. 597 (B.C. Prov. Ct.); [1983] 3 W.W.R. 618 (B.C. Sup. Ct.)
2. *Commision scolaire Chauveau et al. v. Commission des droits de la personne du Quebec et Rouette*, May 20, 1994 (Quebec Court of Appeal).
3. *Re Eve*, [1986] 2 S.C.R. 388.

ANDREW

BY BARBARA NISH

My husband and I have four children: Christopher, Andrew, Cari and Stuart. My son Andrew has some needs that are different from the rest of our children. Andrew is 19 years old.

Our doctor told us, "the diagnosis of your son is that he is profoundly mentally handicapped". He proceeded to tell us the way our life would probably unfold as far as Andrew is concerned. He said that institutions and being institutionalized was not for Andrew and that we needed to take Andrew home, make him a part of our family and treat him like any other child we had.

My father told us that we would run into experiences with Andrew, experiences we would never have dreamed of in our lives. Some would be good and some not so good. He said, "If you can come away with something good (positive) out of every experience then everything will be fine." We have applied this to our lives and taken it to heart. We have made this our creed and tried to instill it in our children.

The doctor said that a child with constant needs can either pull your family apart or pull your family together. It is **not** the child doing this. Instead it is all the "stuff" involved.

When I do the dishes and Andrew comes up behind me, crawling because he can't walk yet, he pulls himself up and gives me a big hug. It is the most incredible feeling that this is **his** way of saying, "I love you." I could go on talking for days about little things like that .

This child has brought more to our lives as a family than any other experience we could possible have had. I don't think I would ask to do it again, but I wouldn't trade it for anything.

The influence he has had on other children is incredible. My 21-year-old son would move out with Andrew if he had the proper support. If I happen to mention alternate living arrangements for Andrew, my 14-year-old daughter goes into hysterics, wanting Andrew to be at home for the rest of his life. If my husband and I died, I wouldn't worry about Andrew.

It has also had a wonderful effect on our extended family. Andrew's influence has extended far beyond what we expected.

This sounds idyllic and as though I am a perfect mother. Therefore, I will tell you a story that is not so wonderful. I had reached a point where I had absolutely had it. Andrew was undergoing surgery and I was pregnant. I began throwing things at my husband and father, screaming, "I don't want to do this anymore! I can't do this anymore! I didn't ask to do this!"

Everyone was scared that I had gone off the edge. I went into my room and cried for hours. I thought, "It's **not** him, it's **not** him, it has to do with the **'stuff'** ..."

I would like to tell parents not to put the blame for all these things on the child, because it is not the child. It is society, friends, the medical field and so on. I feel that sometimes I have to give the impression that I am strong so other parents will also be strong.

One day Andrew was determined to go outside and play. He opened the door and crawled out into the street. My neighbours must have thought I was a terrible parent for letting my child out on the street but you know I celebrated the fact that he opened the door to get out on his own.

It is a matter of looking at the positive things and celebrating the little things. We need to celebrate when Andrew comes up behind me and gives me a hug.

Section IV.

Partnerships in Community Living:

Promoting the Rights of Children through Social Policy

This section explores the specific implications of education, early childhood intervention and health policy and how they include the rights of children to be participating members of their communities.

CHAPTER 10.

The Rights of Children with Disabilities to Medical Treatment: The Canadian Scene

BY ANDRÉ BLANCHET, CANADA

There is a tremendous amount of work to be done in order that children with disabilities in Canada receive medical treatment as would any other child. The legal framework in Canada for the discussion of the right to medical treatment is the *Canadian Charter of Rights and Freedoms*, which was adopted in 1982. Two sections of this *Charter* deal with the rights of people with mental and physical disabilities. The key Section 15 states: "Every individual is equal before the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental and physical disability." Section 7 of the *Charter* states that every citizen of Canada has the right to life, liberty and security of the person. Section 7 is the basis of the right to treatment because, in order to have the right to life and security, both children and adults must have the right to medical treatment. The 1977 *Canadian Human Rights Act*, which has been adopted in all provinces of Canada, says that it is unlawful to discriminate against anyone in the provision of goods and services, in accommodation or in employment because that person is perceived to be disabled.

To reinforce the *Charter* and the *Human Rights Act* are several well-known court cases in Canada dealing with issues affecting people with intellectual disabilities. Many of these cases have been supported by the Canadian Association for Community Living (CACL).

The Stephen Dawson case was one of the most important cases in Canada on the right to treatment.[1] Taking place in Vancouver, B.C., in 1983, it concerned a child who suffered brain damage from a meningitis infection shortly after birth. At just a few months old, the child needed life-saving surgery to implant a shunt in his brain. The operation was done and the shunt worked well until Stephen was six years old when the shunt became clogged, as happens from time to time. At first, the parents consented to an operation to fix the shunt. However, they became convinced by professionals, including the physicians who were caring for the child at the hospital, that the child's quality of life was deteriorating. The parents were told that the best thing would be to let Stephen die in peace at home. His family brought Stephen home to die.

Members of the local parents' association and other staff in the hospital disagreed with the professionals' recommendation and with the family's decision. This group requested that the Superintendent of Child and Family Services apprehend the child. This meant that the child became the state's responsibility, removing the authority of the family.

The intervening group contended that the situation was not as the parents claimed and that, although some professionals were calling it a right-to-die situation, it was really a case of the child's right to treatment. The case went to the Supreme Court of British Columbia where the result was a famous judgement rendered by Mr. Justice Lloyd McKenzie. Justice McKenzie said: "I am satisfied that the laws of our society are structured to preserve, protect and maintain human life and that in the exercise

of its inherent jurisdiction, this court could not sanction the termination of a life except for the most coercive of reasons." In terms of precedents, this case is the legal basis in this country for the right to treatment of children with disabilities.

Re Eve, another important case, dealt with non-therapeutic sterilization and was debated in many courts before going to the Supreme Court of Canada.[2] That court's judgement, rendered in 1985, said that, in this country, it is illegal to sterilize anyone for non-therapeutic reasons without their informed consent. This extremely important judgement makes it a criminal matter for physicians to perform sterilization without consent other than for therapeutic reasons.

Under Canada's social policy framework related to right to treatment issues, provinces are responsible for health and social services and education. Because of this, Quebec is the most interesting jurisdiction in the country. In this province, the civil law is the Napoleonic Code. The spirit of the Napoleonic Code is that legislative principles carry more weight than written judgements and precedents. As one jurisdiction in Canada, I feel that Quebec has many social policies, legislative acts and written regulations on paper that support the principle of full social integration for people with disabilities. Among these is legislation stating that people with disabilities, in principle, have the same right to medical treatment as any other citizen of that province. It is clear that there is a legal and social policy framework for the rights of people with intellectual disabilities in Quebec and across Canada. But, despite that framework, the reality in Quebec, in other provinces of Canada and around the world is very different. My experiences as a physician and the experiences related to me by colleagues, families and advocates show that struggles go on continually for the rights of people with disabilities. Canada has achieved a great deal in so many ways, but there remains a lot to be done.

We know that, despite the legislation and legal precedents, non-therapeutic sterilizations without consent are still performed in this country. I can identify three reasons for the continuation of this practice. First, there is still a tremendous lack of information among physicians regarding the law surrounding non-therapeutic sterilization, despite the fact that all Colleges of Physicians have made the *re Eve* court judgement available for several years and despite reminders by these provincial Colleges to physicians of this law. Second is the interpretation of clinical facts. There is confusion about the notion of non-therapeutic sterilization. There are many nuances and interpretations in diagnosis. The judgements of some non-therapeutic sterilizations as illegal are being challenged by treating physicians and other physicians, who claim that the operations were therapeutic. Many physicians mention the presence of tumors in these cases. If a tumour happens to be in a woman who happens to have an intellectual disability, there is a strong tendency to do a hysterectomy. The third reason is the intangible factors in some of these situations involving often unconscious value-based judgements. Many physicians, and some who have been in practice for a long time, have particular, often unconscious views about people with disabilities, particularly intellectual disabilities, that are difficult to change. These influencing factors are well understood by groups seeking to prevent non-therapeutic sterilizations.

In examining the issues affecting the rights of children with disabilities to medical treatment, one serious problem is the "No Code" practice. In this practice, it is decided, often before a child requires life-saving or any other medical intervention, that the child will not receive any treatment except comfort measures or that no resuscitation will take place in the event of cardiac arrest. Children are subject to this practice in ambulance services, in hospital emergency wards and in intensive care units. Physicians, nurses and health care professionals who advocate for the rights of

children with disabilities and are aware of this practice are faced with a constant fight in these situations, requesting that children with disabilities receive the same treatment as other children.

Again, a factor in this lack of treatment is the conscious or unconscious value judgements made by professionals about quality of life of people with a disability, particularly those with severe disabilities. These judgements have to be questioned. Contributing to these judgements is the fact that health care is a treatment culture. Doctors and nurses make conscious or unconscious decisions along a scale of interventions or treatments. Clearly, people with disabilities do not fall at the top of that scale. This perception is reinforced by economic concerns. There are arguments that, as a society, we cannot afford treatment to maintain the lives of children with severe disabilities.

In response, innovative professional initiatives and approaches are being developed to ensure children's rights. A unique innovation is the Canadian Paediatric Society's Statement of 1986. This stirring pro-life, pro-treatment document states that the physician's role is to provide life-sustaining treatment, except in four extreme situations such as "irreversible progression to imminent death" or "lives filled with intolerable and intractable pain and suffering".

There are also several interesting personal initiatives, one of which is a guideline being used by advocates and family members, as well as with nurses working in hospitals and health care professionals in the community. It is a detailed guideline protecting the lives of people when they go into hospitals. It provides a guide for developing a guardian mentality in community and front-line service providers so that if a child or adult using that service goes to the hospital there is an alert, aware person advocating for that individual's right to treatment. This guideline also addresses open discussions with family members regarding treatment issues so families can safeguard

the treatment of their children when their children have to be hospitalized. There are many other community initiatives that surround a person with a support network which will advocate for that person's rights in all situations.

These personal and professional initiatives are leading communities and professionals in the right direction but are as yet too few and far between. It is not enough to have documents, laws and court precedents that state an individual's rights. Information and education about people's rights to treatment are needed in the medical profession, in service providing industries and in communities across Canada.

NOTES

1. *Re S.D.*, [1983] 3 W.W.R. 597 (B.C. Prov. Ct.); [1983] 3. W.W.R. 618 (B.C. Sup. Ct.).
2. *Re Eve*, [1986] 2 S.C.R. 388.

Chapter 11.

Inclusive Child Care in Canada: Advances at Risk

BY SHARON HOPE IRWIN, CANADA

On issues of social policy, Canada is usually seen as occupying the middle ground between the industrialized European countries with strong social safety nets and the United States with much weaker supports.[1] In comparison to the United States, Canada has the *Canada Health Act*, the Unemployment Insurance program, tax-supported tuitions to universities and Old Age Insurance — all strong, universally accessible programs. The United States' debate over proposals for a national health program is a reminder of the 39 million people without medical insurance in that country, the vastly more limited unemployment insurance program, the $20,000-plus per year tuitions at private universities and the more limited old age insurance programs. In most respects, Canada is seen as having a more supportive social safety net than the United States.

In the case of young children with disabilities, however, the United States has a higher level of entitlements. With Public Law 94-142 through the *Individuals with Disabilities Education Act*[2] giving entitlements to "free and appropriate education in the least restrictive environment" for persons with disabilities ages three to 21, with Public Law 99-457 for

persons 0 to three years of age and with the *Americans with Disabilities Act*,[3] the United States provides rights that do not exist in Canada.

Canadian education lies within provincial jurisdiction and no province has enshrined "free and appropriate education in the least restrictive environment" for persons with disabilities. A few provinces provide some legal standing for the education of persons with disabilities, but recent education rights cases in Ontario only confirm the weaknesses of those guarantees.[4]

Inclusive child care presents an additional set of problems. If "free and appropriate *education* in the least restrictive environment" is not a right in Canada, it is not surprising that rights to *early intervention and inclusive child care* for young children with disabilities have not even begun to be addressed. *In no province is there statutory entitlement for children with disabilities to be included in regular child care programs.* Several provinces do provide home-based early intervention services but these services do not include a "child find" program mandated to locate eligible children and offer services, as they would in the United States. In Canada, even if a centre receives public funds, no anti-discrimination requirement is attached to those funds.

Canadian child care programs that want to include children with disabilities are often plagued with practical barriers such as low salaries, high staff turn over, minimal training, inadequate space and high child-to-staff ratios. Affordability to parents is yet another barrier.

Despite having no legislation and all these practical barriers, many Canadian programs promote and support inclusive child care. Many advocates in these programs promote inclusive child care because of a strong theoretical grounding in normalization theory.[5] Many hold strong ethical or religious beliefs that it is wrong to discriminate. Underpinning both these rationales is the belief, and emerging research to substantiate the belief, that children

with disabilities benefit from inclusion in programs with their typical peers.[6] Other advocates emphasize the value of inclusion for all children — the benefits to typical peers as well as children with special needs.[7] But the fourth leg of the inclusion table, legislative entitlement, is missing. Whereas Americans can look to the law for support of inclusion, in Canada all we have is the yet untested promise of the *Charter of Rights* and provincial Human Rights Codes.

A BRIEF HISTORY OF INCLUSIVE CHILD CARE IN CANADA

THE 1960S AND 70S: SPECIALIZED PRESCHOOLS

Through the 1960s and 70s, Canadian child care was characterized by day care centres and nursery schools. The day care centres were primarily custodial environments for the children of the working poor. They provided a safe environment, nutritious meals and adequate care. Nobody expected them to be much more. For middle class parents, on the other hand, preschool or nursery school was the choice for three- and four-year-olds. The child attended a social program for two hours a morning or afternoon and spent the rest of the day with his or her mother or housekeeper. A parallel system of developmental preschools flourished for children with disabilities. Driven by parents of children excluded from the regular preschools, a strong system of Canadian Association for Mentally Retarded (CAMR, now CACL) nursery schools and Child Development Centre preschools (CDCs) for children with physical disabilities developed across Canada. These programs were characterized by specialization and segregation and by strong parent involvement (particularly the CAMR programs). They often supplied transportation and were free for eligible children. There were few, if any, day care programs for children with disabilities.

THE 1980S: THE TRANSITIONAL DECADE

With growing participation of mothers of young children in the workforce, the need for a setting that expanded the length of the preschool or nursery school program was obvious. Some preschools added a "bridge" program at lunchtime between their morning and afternoon programs to accommodate children of working parents. Some added "wrap-around" programs before 9:00 a.m. and after 3:00 p.m. In addition, the traditional day care centres that had been seen as primarily custodial settings for low-income parents began to expand their developmental or educational components. Almost inadvertently, people realized that among the working mothers were mothers of children with disabilities.

In the 1980s, the child care centre became the characteristic non-parental setting for children aged two to five years. In fact, many more families actually used non-licensed out-of-home care or care by relatives,[8] but it can be argued that the licensed, group child care setting "characterized" the period. Quality measures were developed; training programs and qualifications were strengthened; and provincial legislation began to reflect awareness that child care needed to mean more than "safe and fed". And just as middle-income parents were pressing the system to provide higher quality experiences, parents of children with disabilities were trying to get in. They were in the workforce in greater and greater numbers and needed child care. But they also, individually and as part of advocacy groups such as CACL, were looking for "normalized" or "least restrictive" placements for their children — placements such as child care.

The CAMR nursery schools began to change form and function — first by turning into "reverse integration" settings, where the totally segregated setting became one involving 50 per cent typically developing children and 50 per cent children with intellectual disabilities; then by assuming a support and

consultation role for regular child care programs, as their children moved into these settings.

The Child Development Centre preschools changed more slowly. These were often connected to rehabilitation centres of hospitals, with therapists on site or on staff, and often incorporating accessible physical design features. Understandably, these programs were more resistant to inclusion. If the children went into regular child care programs, what would happen to the therapies? What if the settings were basements, church halls and other "found spaces" characteristic of day care? Was that really the best use of therapeutic time? And, if not, who was going to take the child to therapy? And if that were worked out, who would "integrate" the therapy in the regular day?

At the end of the 1980s, integrated child care for a child with a physical disability would often be characterized by a sliced-up day.[9] The child would go to a regular child care setting when his or her mother left for work, be picked up in the CDC van at 8:30, go to a two-hour therapeutic program for the morning, then be taken by van back to the child care setting for the afternoon. There was anything from non-existent to full coordination between the two programs. But between dressing for outdoors, waiting for the van, riding in the van, waiting to be undressed for indoors, being dressed again for the ride back, waiting for the ride, riding in the van and being undressed again for indoors, children were spending an enormous amount of very passive time.

By the end of the 1980s, despite the lack of legislated entitlement, Canadian child care programs were enrolling more children with disabilities, in programs increasingly inclusive.[10] Modest financial incentives, additional training, strong parental advocacy and a growing awareness of the benefits of inclusion encouraged this change.

THE CURRENT SITUATION: POLICY AND PRACTICE

By the beginning of the 1990s, from the perspective of inclusion, the Canadian child care non-system could be summarized as follows:

1. LEGISLATION AND POLICY

Legislation and policy were beginning to catch up with the models of inclusive child care across Canada. British Columbia, Saskatchewan, Ontario, New Brunswick, Nova Scotia and Prince Edward Island were rewriting their child care legislation, as it related to children with disabilities. The dominant feature of new legislation was some attempt to support children with disabilities in regular child care settings, rather that to support a separate, segregated track.

British Columbia has been notable for its special needs review.[11] The ministerial response to the recommendations of the Special Needs Review Task Force will be released by autumn 1994. With great respect for local histories and local strengths and needs, the recommendations will raise the baseline of social policy in Canada as it relates to preschool children with disabilities.

On the other hand, Ontario's strong move toward a policy of family-centred, inclusive child care has been slowed, if not halted, by a governmental decision not to continue with child care reform in areas where new dollars are required.[12]

Nova Scotia's draft regulations[13] are currently being circulated for comment. They use the language of inclusion and move provincial child care regulation away from an add-on model of addressing special needs towards one that encourages the participation of children with disabilities in community-based programs. Notably, Nova Scotia has begun to support 10

per cent of its new child care spaces with "differential funding", recognizing that approximately 10 per cent of children will require additional supports to successfully participate in child care programs.[14]

New Brunswick's 1993 regulations improve provincial supports for children with special needs, but provide less support to the regular child care programs into which these children will be integrated.[15] Saskatchewan's legislated changes speak positively about "special needs," but fiscally are very limited.

On the federal level, the discussion document on Social Security Reform[16] addresses issues of children with special needs at several points, relating both to parental employment and to healthy child development. Current federal arrangements that affect child care do not mention "children with special needs" (e.g., the Canada Assistance Plan and the Dependant Child Allowance).

2. PRACTICE

Despite the lack of legislated entitlement, Canadian child care programs are including more children with disabilities. Irrespective of provincial legislation, urban or rural status, or funding, SpecialLink researchers found innovative programs in every province.[17] The quality as well as the quantity of inclusion has increased significantly. Programs that had formerly included only children with mild to moderate disabilities are beginning to include children with tougher challenges. Partnerships between child care staff and early intervention staff have been strengthened in many settings. Collaborative efforts such as team planning, transdisciplinary service delivery and arena assessments are becoming more prevalent.

THE FRAGILITY OF "INCLUSION" WHEN NOT BACKED BY LEGISLATION: A CASE HISTORY

It is time to tell a true story — a story about one of the best inclusion programs in Canada. It is a simple story that points out the need for legislation to support the best of what has been achieved.

Let's call it The Children's Centre. It is a non-profit centre into its 15th year. In its earliest years, commitment was unswerving. Staff often took turns in the winter sleeping on the floor to ensure that someone would be there in the morning in case it stormed. And right from the beginning, the centre included children with disabilities. Initially there was no driving philosophy — they just couldn't say "no" to one particularly persuasive parent. As time went by, they added skills to willingness and moved through the predictable stages to a fully inclusive program.[18]

The staff of The Children's Centre took pride in their principles.[19] The principles of inclusive child care are:

- Zero rejection — no child will ever be excluded for reasons of level or type of disability.
- Natural proportions — the program includes children with disabilities roughly in proportion to their occurrence in the general population.
- Same range of options — children with special needs must not be limited to shorter child care days or excluded from home-based or school-aged care.
- Full participation — necessary supports must be provided so that all children can participate in some way in all activities.

- Advocacy, proaction, parent involvement — the program must actively lobby for legislative and policy change, must actively encourage enrollment of children with disabilities and must involve parents at the level parents choose.

Over the years, The Children's Centre deliberately included children with multiple handicaps, children with profound disabilities and children with exceptional health care needs. In the absence of appropriate training, they developed their own training programs. They became a model of inclusive child care for Canada — attracting visitors from the United States, Europe and Africa. And, throughout it all, they remained a regular child care program, without bells and whistles, without extra financial supports not available to other programs in their province.

The Children's Centre experienced very limited staff turn over, always had long waiting lists and was a source of pride in its community. In fact, when this incident occurred, four frontline child care staff were preparing to teach a summer course on inclusive child care at a neighbouring community college. Here is what happened.

An admissions committee meeting had just been held to review the waiting list of children with special needs and to determine when and where they would be enrolled. When the meeting was over, the group congratulated itself on having found a plan to meet everybody's needs. Then one staff member said, "Too bad we weren't able to include Hannah."

Everybody else was silent. The usual formal admissions process had just been followed, and all the applications had been reviewed. Hannah had not been mentioned.

And everybody at the admissions meeting *knew* about Hannah. Hannah had spina bifida and required catheterization. Hannah's mother had never *formally* applied for admission. Instead, she had asked her sister-in-law (an employee at The Children's Centre) to inquire about her daughter's possible attendance. Informally, the sister-in-law asked some other staff, who said they wouldn't be comfortable catheterizing the child. Sister-in-law reported back to mother, who then didn't go further in the admissions process. But everyone knew there was a child with special needs in the community looking for care. It was a soft cry for help. In the old days it would have been heard loud and clear. But 15 years later, no formal request was made and no one was going to hear the cry.

In short, the staff of one of the most inclusive child care centres in Canada found themselves ducking a child with special health needs, ducking a tougher challenge. They had relaxed their principles and they had no legislation to remind them to be their best.

Lest I leave you wondering about what happened: the mother was encouraged to visit the centre and to fill out an application. Hannah is now attending The Children's Centre. The staff follow the guidelines of the *Special Health Care Book* which includes awareness training, general procedures and case-specific training.[20] No staff person is forced to do anything that makes her or him uneasy. And staff now wonder why they had hesitated to include Hannah in the first place.

All outcomes are not this happy. More often, a Hannah would be excluded.

Despite the development of more and better inclusive child care services, advocates and parents remain understandably

apprehensive about the stability of inclusive child care programs. Program founders move on. Commitment is a hard thing to pass on to new staff. Increased bureaucratization, growing professionalism, unionization and formalized policies and procedures can create new barriers. And people get tired and need to be reminded to rise to their best. Without legislation or regulatory support that calls on child care centres to include children who need extra support, it is easy to fall back into old ways, finding barriers rather than creating opportunities. Only legislated entitlement can protect the gains of inclusive services from the erosion of fiscal restraint, staff changes and trendier issues.

Legislation won't save us — but it will keep us on track. Advocates must decide what kind of legislation is required. For instance, during a phase-in period, it might be better to offer incentives to include, rather than penalties for exclusion. What would these incentives be? They would be training, funding, support, physical adaptations and consultation.

CONCLUSION

Despite the absence of legislation or social policy that provides entitlements to early intervention and child care for children with disabilities, Canada has witnessed substantial development of appropriate services. However, these services rest on "discretion" rather than "mandate" and so are at risk of disappearing or shrinking in times of fiscal restraint and changing governmental priorities — or even the aging of the advocates and staff. It is essential that Canadian legislation — both federal and provincial — assure entitlement of children with disabilities to inclusive child care and early intervention services.

NOTES

1. L. McQuaig, *The Wealthy Banker's Wife: The Assault on Equality in Canada*, Toronto, Ont.: Penguin Books, 1993.
2. *Individuals with Disabilities Education Act* (IDEA), Code of Federal Regulations, Vol. 34, 1992.
3. *Americans with Disabilities Act* (ADA), *U.S. Code*, Vol. 42, sec. 12101-213.
4. York Region Board of Education press release, York Region, Ontario, 1994; "A Learning Experience for Us All", *Ottawa Citizen*, March 4, 1992.
5. W. Wolfensberger, B. Nirje, S. Olshansky, R. Perske, P. Roos, *Normalization: The Principle of Normalization in Human Services*, Downsview, Ont.: NIMR, 1972.
6. P.S. Strain, "Least Restrictive Environment for Preschool Children with Special Needs: What We Know, What We should Be Doing", *Journal of Early Intervention*, 14(4), 1990, pp. 291-296.
7. C.A. Peck, P. Carlson and E. Helmstetter, "Parent and Teacher Perceptions of Outcomes for Typically Developing Children Enrolled in Integrated Early Childhood Programs: A Statewide Survey", *Journal of Early Intervention*, 16(1), 1992, pp. 53-63.
8. D. Lero, H. Goelman, A. Pence, L. Brockman and S. Nuttall, *Parental Work Patterns and Child Care Needs. Report from the Canadian National Child Care Study*, Ottawa, Ont.: Statistics Canada, 1992.
9. S.H. Irwin, *Integration of Children with Disabilities into Day Care and Afterschool Care Systems*, Ottawa, Ont.: Health and Welfare Canada, 1992.

10. Ibid.

11. British Columbia, Special Needs Day Care Review Reference Committee, *Supported Child Care*, British Columbia: Minister of Supply and Services, 1993.

12. Ontario Coalition for Better Child Care (OCBCC) press release, 1993.

13. Nova Scotia Round Table on Day Care and Day Care Services, Day Care Licensing Manual, Discussion Paper (Draft), 1994.

14. Dr. James Smith, Minister of Community Services, Halifax, Nova Scotia, press release, 1993.

15. New Brunswick, *Early Childhood Initiatives: An Overview*, New Brunswick: Department of Health and Community Services, 1993.

16. Canada, *Social Policy Reform: The Federal Discussion Paper*, Ottawa, Ont.: Human Resources Development, 1994.

17. Irwin, *Integration of Children*, 1992 (see n. 9).

18. S.H. Irwin, "SpeciaLink Newsletter", 2(1), 1991, in Irwin, *The SpeciaLink Book*, Nova Scotia: Breton Books, 1993.

19. SpeciaLink, *Children with Special Needs: The Need for Child Care*, Nova Scotia: SpeciaLink, 1993.

20. T. Norton, *Special Health Care: Recommended Practices for the Early Childhood Education Field*, British Columbia: Fraser North Childcare Issues Society, 1993.

CHAPTER 12.

Learning from Our Experiences in Education Policy: The Story of Segregated Schools in the United States

BY MICHAEL REMUS, U.S.A.

Countries have an important tool in developing social policy that addresses the needs and rights of children with disabilities — the experiences of other countries. Nations can learn a great deal from one another about developing effective social policy. In the United States, we are fortunate to have many progressive policies and laws on paper, but it is useful to examine how they have been implemented and used. One such area is education policy.

In 1975, a federal law known as Public Law 94-142 was passed. It stated that all individuals with disabilities would receive a "free appropriate education", despite their level of disability. This law stipulated that free appropriate education be provided in the "least restrictive environment" (LRE). In other words, the goal of the people drafting the law was, at that point in time, to educate students with disabilities alongside non-disabled peers in the least restrictive environment.

However, the law was interpreted differently by people across the country. People had different perceptions, different

definitions and different connotations of the wording of the law. As a result, in the late 1970s segregated facilities cropped up everywhere across the country — segregated schools, segregated classrooms, self-contained classrooms and so on. These segregated services were being interpreted as the least restrictive environment because the children they were serving were, at the very least, leaving their homes, where they had nothing to do, on a daily basis. However, the children were isolated at home and they were isolated in these services. Several of the law's original authors were furious at having their words interpreted differently by so many people. And once those segregated facilities came into existence they became firmly entrenched in the education system. The past 15 years have been spent in efforts to reverse the trend and eliminate segregated facilities.

The lesson to learn from the United States is "don't do what we have done". We have made serious mistakes despite having social policies and legislation in place. It is important to realize the years of children's and families' lives wasted by this misinterpretation. What can be drawn from this experience is that, with current laws and social policies, one of the first issues is to define up front how the words will be interpreted, taking into account semantics and other people's understanding of language.

We found, in the U.S., that understanding LRE or least restrictive environment went through various phases. Educators and professionals came up with the word "mainstreaming", which meant including children in regular education opportunities. Although the word mainstreaming does not even appear in the law, it became the "buzz term" to refer to least restrictive environment. The term "mainstreaming" was then replaced by "integration". We moved into the era where we integrated students. Finally, in the last four to five years we have talked about "full inclusion". The problem has arisen here again: we are having a difficult time defining full inclusion. Some people interpret it as

placing students with disabilities in regular classrooms all the time, no matter what their needs are — even if their needs may not be met in that setting. Here again, we need to define the issues that may surround this particular idea in order that we do not regress.

LRE is defined by basic rules. One is that children have to be educated as "close to home as possible". Now we talk about children being educated in their neighbourhood schools where others in their community or neighbourhood would go to school. Another rule is "placement in the same schools with peers unless IEP services necessitates another more restrictive placement." A third basic requirement of LRE is inclusion in non-academic and extra-curricular activities. It was found that students were in the academic situations, but what about sports and social activities after school?

In 1984, the federal Office of Special Education Programs (OSEP) defined its view of LRE: "Educational reasons do not exist to justify the movement of children with disabilities from integrated educational programs to more restrictive settings. States should strive to prevent and discontinue the placement of children with disabilities in settings more restrictive than the regular educational environment". In other words, there was a very good law in place but nobody was paying attention to it or acting on it the way it was intended to be. During the 1980s, the federal government left schools alone and overlooked the existence of segregated facilities and classrooms. In the federal government's view, states were delivering an appropriate education, meeting the intent of the law.

Families felt that their children were not receiving a quality education. Families, self-advocates and parents groups were looking for the removal of the words "least restrictive environment". They wanted them replaced with "inclusion", because they felt there is a difference between the two terms. Students can physically be in a least restrictive environment and not be truly included. On the

other side, educators and professionals wanted to keep least restrictive environment because it gave them leeway to provide a continuum of services, which could include segregated facilities and programs. Students were placed in segregated settings and had to prove their ability to move through a progression of less restrictive settings to reach the regular classroom. It was a war over differences in definitions.

In 1986 views began changing. The national goal became to decrease the number of people with disabilities who live, work and are educated in restrictive settings. According to OSEP, states and local districts were required to develop criteria for making placement decisions and to justify the placement decision as LRE. If a decision was made for a student to be separated from the regular school environment based upon the availability of certain services, then OSEP asked, "What is different about these services that they cannot be provided in a regular school setting?" Finally, after 11 years of talking about free appropriate education, the government decided to give funding only to school districts, programs or agencies that truly followed the least restrictive environment rule. The government said that schools had to begin phasing out segregated facilities.

In 1989, the *Daniel R.R.* v *El Paso Independent Schools* case resulted in a decision that defined a two-step test for the inclusion of a child with a disability:

- Has the school district made every attempt to educate the child in the regular education classroom, including making available supplementary aids and services?
- If a regular classroom is inappropriate, has the school district provided other opportunities for inclusion, such as lunch, recess and field trips.

In 1990, the movement towards inclusion grew stronger and OSEP stated that: "all children with disabilities regardless of the severity of their disability, have the right to be educated in the LRE in which an appropriate education can be provided."

Major Supreme Court cases have been instrumental in moving the issue forward. The first, occurring in the fall of 1993, was the Oberti decision (Oberti is a student in New Jersey), which became the cornerstone of the OSEP position: "Inclusion in the regular school is expected and inclusion in the regular classroom is preferred." According to the Oberti decision, "We construe IDEA's (*Individuals with Disabilities Education Act*) mainstreaming requirement to prohibit a school from placing a child with disabilities outside of a regular classroom if educating the child in the regular classroom, with supplementary aids and support services, can be achieved satisfactorily." Schools are now required to document reasons for removing a child from a regular education placement and they must satisfy three questions before making that placement.

In the second influencial Supreme Court case, *Sacramento City Unified School District* v *Holland*, the school felt that, because of her disability, Rachel Holland would function better in a more restrictive environment. In response, Rachel's parents took her out of the public school system and put her in a private school. They documented her progress for the year she was in private school and proved that she did as well as all the other students in her classroom. At that point they took legal proceedings against the public school district.

These two court cases have made school districts begin to look at their own practices. Although in many places segregated education still occurs, the number of segregated facilities is decreasing. In addition, at least there is a great deal of discussion going on, particularly as a result of the efforts of advocacy groups.

Finally, LRE is being seen as a human rights issue and that underlying this legal protection is the moral belief that all people, including those with disabilities, have a basic right to freedom. In the case of LRE, this right protects from capricious or unjustified restrictions on one's liberty in educational settings. Ultimately, obeying the letter of the law means providing as much inclusion as possible. Courts are now requiring schools to do more than merely speculate that a regular education placement will not succeed. Courts are requiring school to attempt regular education placements and prove that these placements will not succeed before they will approve of a child's removal from the regular environment.

Finally, in many parts of the United States, inclusion in education is being defined as:

- all students learning in the same school with the necessary services and supports so they can be successful;
- each student having his or her unique needs met in an integrated environment.

It is likely that the experience in the United States with education policy happens in other countries. People follow their values or belief systems. Laws and court cases do not make a difference in how people live, in their values and morals and in how they view human rights.

Families that fought long and hard for the educational right of their children are tired. Now young families, who have had the benefit of services and have felt entitlements won by the former generation of families are beginning to address quality and inclusion issues. Networking and learning from other families, other communities and other countries, expecially from their mistakes, will help countries move ahead more quickly towards achieving full inclusion of people with disabilities in all facets of society.

Olivier

BY COLETTE SAVARD

Preparing for the birth of a child is like preparing for a trip. You hear of friends going to Italy and they come back with all sorts of nice things. They tell you how beautiful and colourful everything is — the flowers, the museums, the sea — and how the music is enchanting. And you say to yourself, maybe I should visit that country too. So you begin to prepare yourself. You get brochures and you go to the library and read about the country's history. It becomes exciting as you get ready for your trip.

Everything is set but on the flight across the ocean, the pilot tells you that he is sorry but the plane will have to land in Holland. You are upset because you don't know anything about Holland. You don't know what sights to see or what museums to visit. But you have to make the best of it. And, during your stay, you find that Holland is also close to the sea, though the sea is a different colour. In Holland, there are many beautiful flowers too. The scents and types may be different but just as beautiful. There are museums, there is a history and the people you meet are very nice.

Then you come back home and you tell your friends and relatives that you had a nice trip. It was different, but you share all your experiences with your family and friends, and to you the trip is valued.

It is like this when a child is born with a disability. You were prepared for a different child. But this is a new, enriching experience that will sometimes be nice and sometimes very difficult. You may feel isolated. You may not know what to do. The first thing to do is to communicate with families that have had the same experience so you can learn from their successes and challenges.

One challenge I remember well is a meeting I had with a psychiatrist, who told me that I was not an able mother because my son could not speak at the age of four and a half years. He told me that children are supposed to learn from their mothers. But Olivier was not my first child. I didn't have problems with my other sons. I kept wondering if it was really my fault that Olivier could not speak. Was it a measure of how good a mother I was? Now he speaks so much, you sometimes wish he would stop for a while. I wish I could go back to that psychiatrist to show him how well I did.

Recently I was attending a conference where they were talking about parents. One father talked about how his family was up to its ears with difficulties and that there was so much discomfort in their lives they could not cope with it any more. I had to tell him my story. Olivier is the best gift I have ever been given. A gift is something you don't choose at all. You look at this gift and wonder what you can use it for. I found it was something that made my life so rich and I have learned to grow from him. I am not saying it is easy, but Olivier is the nicest gift ever given to me in my life.

SECTION V.

PARTNERSHIPS IN COMMUNITY LIVING:

Strengthening Communities through Policy and Program Initiatives

The chapters of this section explore how social policy for children and youth with disabilities and their families can strengthen communities.

CHAPTER 13.

Services that Hurt and Services that Help

BY MICHAEL MENDELSON, CANADA

In a healthy community, every person maintains many human relationships of varying degrees of intensity. Some relationships are with people we can call on to help us and who can call on us to help them. These people are, first, members of the immediate family and the extended family, then friends and people in the wider community. These relationships are like a series of concentric circles. Usually, the help that each of us can call on is greatest within the inner circles and lessens as we widen our net. Within the family, a kind of primitive communism is often the rule. It is probably the only place where the rule "from each according to their ability, to each according to their need" is commonplace. The extended family also often embraces a degree of altruism for its members that exceeds the expectations we have of all but our closest friends.

The concentric circles differ from person to person, from place to place and within a lifetime. For example, in urban centres in Canada, ethnic networks define the "community" to which many Canadians feel most strongly connected. In Canada's rural communities, physical proximity among people is likely a much more important factor. No matter how our circles are defined, the stronger they are the more we can help one another. And, in my

experience, everyone at some time needs the help that family, friends and community can provide. This is no different for persons with a disability.

Beyond our personal relationships, we are also part of wider, formal communities defined by our various local, provincial and national governments. In a sense, we can think of the state as the widest circle of all. It encompasses everyone in a modern nation in the obligations and rights defined by its laws and rules.

Unfortunately, the laws and rules of the state may conflict with our natural helping and supportive relationships, rather than reinforcing them. In the most extreme case, the state can consciously attempt to make these relationships illegal. The state itself then works to erode community and undermine the core human relationships that provide us with our basic sense of identity.

In a modern, secular state such as Canada, social services are the instrument through which the state intervenes in the most intimate of our human relationships. We are used to thinking of social services as benign and helpful; more is better and less means sacrifice. However social services are not necessarily benign. Where the law and the rules of the state mandate social services to build upon and reinforce our natural supportive networks, social services can also be exactly the opposite of benign. At the most extreme, social services can act as an enforcement mechanism for a hostile state bent upon cultural oppression.

To clarify the ways social policy can strengthen communities, we can look first at how it could and has done the reverse. The most glaring example of social services that have weakened and undermined community has been with respect to Canada's aboriginal First Nations. In a review of child welfare among First Nations, Andrew Armitage argues that:

> *From the passage of the* Indian Act *in 1876 until the 1960s child welfare for First Nation people in Canada was dominated by the policy of assimilation, which used*

educational methods to change the culture and character of their children. Church-operated residential schools were the central institution used in this strategy. When the policy of assimilation was replaced by the policy of integration, the residential schools were replaced by the child welfare strategy in a second attempt to ensure that the next generation of Indian children was different from their parents.

Beginning in the 1960s, social workers from non-Native agencies would periodically visit Indian reserves to pick up children, sometimes as planned "invasions" supported by armed police. These children often ended up in a series of foster homes or were placed for adoption. Few ever found their way home again, at least as children.

The assumptions behind this approach — that child welfare agencies could reliably find suitable loving and nurturing homes and that, even where there where such homes, these could reshape a child to be part of an alien culture — were mistaken. The consequences for the children were sometimes disastrous.

The effect on the children and their families has been documented elsewhere. I want instead to point to the effect on the Native community that remained behind, to illustrate how social services can strengthen or, as in this case, weaken communities.

An extreme analogy provides an example. In a nation under occupation by a foreign power, or under the control of a malignant regime, obeying the law can be an act of acquiescence or worse. What is an ordinary citizen in such a country to do if they know about a crime having been committed? Report it to the authorities? Obviously, this would be unacceptable. In this situation, the response that would ordinarily be the very basis of good citizenship is instead forced "underground" and in the laws of occupying regime becomes illegal.

This is similar to the situation of a Native person on a reserve in the 1960s trying to decide what to do about child abuse or neglect. If the abuse were reported to the authorities, the result would likely have been the permanent disappearance of the child into an alien culture. This would often occur without any of the elaborate due process that surrounds removing a child from its home in the non-Native community.

In the 1960s and 70s, child welfare services on a reserve become a tool Canada used to suppress and change Native culture. This is not to question the motive of social workers and policy makers involved. Many were extremely dedicated and believed that the right thing was being done. But it was not. The natural helping networks of Native communities were not just unsupported, they become illegal and the weight of the state was used to prevent these networks from functioning. The means through which the community would act to protect its children — for example, by the elders of the band placing the child with its extended family — were prohibited. These acts could only be carried out by the non-Native child welfare agency. The community's own helping networks were systematically made illegitimate and destroyed.

Although Indian child welfare services in Canada in the 1960s and 70s may be the most blatant example of social services weakening community, there are others. The institutionalization of persons with disabilities is another example of a social policy that undermines and weakens community. The policy of routinely placing people with disabilities in institutions conveys a clear message to families, friends and neighbourhoods: they are not competent to provide support for those with disabilities. Until recently, families with a child with a disability often came under intense pressure from the medical, psychological and social work professions to institutionalize their children. The "normal" thing to do, they were told, was for any person with an intellectual or physical disability to be taken out of the community.

Although this policy did not actually make it illegal to keep a child at home and keep a family together as was the case for Native child-nurturing networks, it did mean that the full force of community disapproval was brought to bear on those who did not institutionalize their children. It is also meant that there was little or no development of community resources needed for persons with disabilities to participate fully in society. For example, until the return of Vietnam veterans to the U.S., few cities thought of such simple measures for people with physical disabilities as bevelling street curbs at intersections.

For those with an intellectual disability, there were little or no resources or assistance available. Everything from medical and dental services to vocational and community residential alternatives were, at best, available to a few people on a hit-or-miss basis. Families demanding the development of networks of community-based assistance were told that those demands were unreasonable. They should just accept placing their children in an institution.

Again it is important to recall that the helping professions supporting the policy of institutionalized were sincere and believed themselves to be working in the best interest of the families and those with disabilities. They were just reflecting the prevailing consensus at the time.

Although there are many other examples of social policy that weakened communities, the point is not to argue that social services are undesirable — instead it is to argue that the ability of social services to strengthen or weaken communities depends upon the nature and design of services. Social policy can play a critical role in strengthening communities if services are designed to build upon and support natural helping relationships.

As a Deputy Minister in the mid-1980s, I was involved in two initiatives whose goals were to "turn around" child and family services for Natives and to stop and reverse the institutionalization of people with intellectual disabilities. These experiences are

examples of attempts to design and reform social policy so it strengthens communities.

Increasing militancy and active resistance from the Native communities, essentially making it impossible for non-Native agencies to enter some Manitoba reserves, was coupled with high profile incidents and Patrick Johnston's exposé of Native child welfare.[1] As a result of these tensions, in 1981 the Manitoba government, the political leadership of Manitoba's Indian community and the federal Department of Indian Affairs set out to negotiate the establishment of Native child welfare agencies on the reserves. By 1985 all but one reserve in Manitoba was served by fully mandated Native child and family service agencies. The agencies were under control and administration of band councils, so they were now an instrument of the Native communities themselves.

In Winnipeg, which is the only sizable city in Manitoba, there was also a demand from the large Native population for control of their own child and family services. Establishing a mandated welfare agency in the city would raise complex issues about coordination with non-Native agencies in the same geographic area. Instead, a non-mandated Native agency was established which could provide full range of child and family support, but could not take the children into care.

The new agency was named Ma Mawi Wi Chi Itata. Its philosophy summarizes well the theory and meaning of Native child welfare:

> *We understand the child welfare system as a system which has evolved, in the dominant culture, to deal with the problems of industrial society. Within the Native community, the child welfare system is a system that deals with the symptoms of larger social problems — racism, poverty, underdevelopment, unemployment, etc.*

> *The theoretical base of Ma Mawi Wi Chi Itata Centre is grounded in the understanding of child welfare problems as the result of the colonial nature of relations between the aboriginal people and Euro-Canadian majority ... We understand our practice, which flows from this theory, as a process of decolonization. We see this as a conscious process through which we gain control over our lives and resources.*[2]

Although it is evident from this eloquent statement that the Native child welfare system now has the capacity to strengthen community and began a process of healing among Native families, the healing process will be long and difficult. Just as it took more than one generation to subvert Native culture, it will likely take more than one generation to reconstruct that culture.

Several difficult cases have come to light: children who were not adequately protected by the Native agencies; political issues within the Native community interfering with service provision; and gender issues, to mention a few. But for every case of a child abused within a Native family who perhaps should have been taken into care, it is unfortunately easy to find an example of a child abused while within the care of a non-Native agency. There are no easy answers in child welfare.

To strengthen its own community, the Native agencies must be allowed to make their own mistakes and to evolve and change in a distinctive way reflecting Native culture. There will be nothing easy about this. Nevertheless it is the only path promising hope and the possibility of redeveloping a healthy community.

The mid-1980s were a time of change in Manitoba social services. In early 1984, the Manitoba government announced a new policy of deinstitutionalization for persons with intellectual disabilities. Today, such a policy is old hat, but in Manitoba at that time social policy as it affected people with intellectual

disabilities was dominated by the "experts" at the largest institution. The new policy was a radical departure for Manitoba and was intensely resisted by institutional services providers, by many families who had placed one of their members in the institution, by religious orders running institutions and by much of the media. The strength of this resistance showed the extent to which the community had been eroded by the policy of institutionalization.

On the side of deinstitutionalization were the Association for Community Living—Manitoba, a few enlightened social policy activist, the few existing community service agencies, families who had managed to keep their children with an intellectual disability out of the institution and, of course, unanimously, people with intellectual disabilities themselves.

The most difficult problem to be confronted was not finding places for people coming out from the institution. By transferring the funding from the institution this was possible to do without additional long-term cost. The real problem was rebuilding the community-based services for the many thousand of persons with intellectual disabilities already in the community. Because the policy was one of institutionalization, the community-based services, meant to support the natural networks of help, had been ignored, underfunded and were at best a chaotic jumble of ad hoc arrangements.

Among the measures taken were a substantial increase in funding for all community-based residential facilities, the establishment of day programs for adults, the more active pursuit of employment possibilities and the establishment of a special, completely flexible fund to develop individual plans where problems were being encountered and the arrangement in the community was threatened. Admissions to the institutions were halted completely.

Education had to be considered and a special program to accustom medical and dental service providers to the needs of persons with intellectual disabilities was put in place. Ethnic communities were encouraged to take responsibility for establishing their own community residences. All of this was done in very close cooperation with the Manitoba Association.

This was a process of rebuilding community by supporting the helping and caring networks that existed naturally — the family and neighbourhoods or ethnic communities. Again there were many up and downs. Furious opposition remained among institutional service providers who used the mantle of "expertise" to argue that community placement was unsafe. At the same time, they campaigned for more resources for the institution. Naive but well-meaning media gladly took up human interest stories featuring failures in community care but rarely asked about conditions in the institutions. Those institutions were out of sight and assumed by popular consensus to be places of safety. Finally acceding to political pressure from the constituency representing the largest institution, a new Manitoba government reversed the policy. New admissions to the institution resumed, and continue today.

Nevertheless much progress was made. New funding and programs for community living were in place. Community support agencies become stronger. The expectation of families had begun to change. These gains have not been lost and can be built upon in the future when another opportunity arises.

In these examples, important steps were taken to use social policy to strengthen community. However, there are also examples where previous social policy has been used to weaken community and erode natural supportive networks. My conclusion is that good social policy and the strengthening of community are in fact one and the same, and that social policy can be an effective instrument to help strengthen community.

Putting this in practice, however, is never a simple task. It is requires clear understanding of the basic values underlying the need for change, mobilization of communities that want and need change, willingness to take risks in the public arena and strong and continuing political commitment to overcome the obstacles and setbacks that inevitably occur.

NOTES

1. Andrew Armitage, "Family and Child Welfare in First Nations Communities", in B. Wharf (ed.), *Rethinking Child Welfare in Canada*, Toronto: McClelland and Stewart, 1993, p. 131.

2. For example, Patrick Johnston, *Native Children and the Child Welfare System*, Toronto: James Lorimer and the Canadian Council on Social Development, 1983.

3. Ma Mawi Wi Chi Itata, *First Annual Meeting Report*, Winnipeg, 1985, as cited in Armitage, n. 1, p. 159.

CHAPTER 14.

Strengthening Communities through Policy and Program Initiatives: The Latin and Caribbean Reality

BY ANA MARIA DAMINI DE FRAPPOLA, URUGUAY

The *United Nations Convention on the Rights of the Child* and the International Year of the Family are calling on us to reflect on their outcome. More urgently, millions of children and youth are calling on us to be accountable. In fact, 195 million youth in Latin America and the Caribbean are our judges. What are we to say to them? A *Convention* was passed, the World Summit for Children was held, progress has been made, yet the basic rights of many children have not been fulfilled.

Coming from Latin America and the Caribbean, we witness the often difficult reality of the youth of this Region. In this Region, one out of 10 youth may present a disability. This group of children and youth is one of those most affected by the many problems facing Latin American and Caribbean countries. And we cannot but be hit daily by the demand to do something more than just speak of what needs to be done. The demand is for concrete action.

Documents by the Inter-American Children's Institute and by other organizations for the International Decade of Disabled

Persons state that, despite undeniable progress in programs, legislation and services, as well as increased visibility of persons with disabilities, we must ask: Have we been able to reduce conditions leading to disability? Have we been able to improve the well-being of children with disabilities and their families? Have we succeeded in integrating these children into society and into the general stream of policies? Finally, have we made these people's lives better with the programs and options that we have designed for them?

If we are not pleased with the answers to these questions and if the well-being of these people is still a dream, we have to pursue different strategies. If, because of social and economic factors, we predict an increase in disabling conditions, not enough is being done. If the issue of disability is absent from national general legislation, social policy plans or reports on health, education, childhood and social development, because it is thought to be a matter of a "special" sector, the rights of children and adults with disabilities will not be fulfilled. If we accept the passing of special laws that are not part of general policies, we are not on the right path. If policy makers, professionals, managers, directors, division heads, families, persons with disabilities themselves and society as a whole do not recognize that the issue of disability is everyone's responsibility rather than that of an isolated sector in society, we will not obtain the desired result. If services are not adequate or accessible to all youth, we have to find different strategies.

MOVING TOWARDS THE ANSWERS

In looking for new strategies, it is helpful to examine the realities of life that have an impact on people with a disability.

POLITICAL AND SOCIAL PERSPECTIVE

Of the nearly 200 million youth under 18 living in our Region — almost half of the population of the Continent — approximately 50 per cent live in conditions of poverty. Added to this poverty, youth are faced with a social crisis of values, conflicts, institutional instability, frustration and disbelief in the answers to their problems offered so far.

Moreover, youth see their countries affected by rapid technological change and goals of economic progress. However, these goals often originate in countries where economic realities are different or these goals result from Regional agreements that emphasize competitiveness and excellence. The panaceas of technology and economic prosperity have a complex effect on a society's vision of a child with an intellectual disability. There is also a gap between desirable models of what life can be, again often originating in countries with different economic realities, and the fact of what is truly possible, what people may feasibly have, in Latin American and Caribbean countries. This gap must also be considered in terms of its impact on people with disabilities.

POLICIES

Policies affecting persons with disabilities have originally focused on segregationist perspectives. The historical vision was that persons with disabilities were dangerous and society had to be protected from them. The more recent charity perspective saw that people with disabilities had to be protected from society. The result of both perspectives was temporary or permanent institutionalization.

In the Latin American and Caribbean communities, the incidence of permanent institutionalization has not been

significant because of a cultural emphasis on families remaining together. Children stay at home until they are married and families care for people who are disabled or elderly at home. However, socio-economic factors facing middle class families or those in low-income, urban settings might change this situation.

In the 1980s and the early 1990s, there has been a trend towards community inclusion, as well as the participation of persons with disabilities and their families in the design and development of policies that affect them. This new perspective promotes the vision of persons with disabilities as citizens entitled to the same rights as any other citizen. At the same time, disability is beginning to be seen as a social policy issue rather than an illness. So far, this vision of the 80s and 90s has not been fully achieved. However, families have gained a stronger voice. They have developed national organizations and played a unique role in advocacy, which has led to new laws. Recently, they have gained a voice in policy planning and development. Representatives of parent organizations have recently become members of the National Commission on Disabilities.

LEGISLATION

Although there have been great legislative accomplishments in the 1980s, representing a great step forward, the promotion of "separate" laws has resulted in a "separate" vision of people with disabilities. These laws have often segregated people. Many laws have been passed in different countries, some of them directed at policy levels such as the creation of a National Commission on Disability Legislation. The commission is a mix of governmental and non-governmental bodies.

SERVICES

Services are insufficient, meeting no more than 2 per cent of people's needs. Families often have a hard time obtaining the

most basic services such as diagnosis or explanation of a disability. Services provided to persons with disabilities are segregated and segregating, available only in institutional settings rather than in the community. Families have little or no input into service design. Services have been planned mostly from the perspective of the professionals or institutional authorities delivering them.

WHAT IS THE ANSWER?

A new century is already here, offering the fulfilment of many dreams. And what are these dreams? They are of a good quality of life for all; a healthy human environment with respect for differences and cultural identities; respect for good ethics in their broadest sense; a society promoting health, the amelioration of disabling conditions and the participation of all people in exercising their full rights.

HOW THIS CAN BE ACHIEVED?

The 80s brought new approaches, such as the human rights perspective of disability linked to the idea of inclusion. But this perspective, to be implemented, requires new strategies:

1. DEFINING THE KIND OF POLICY WE WANT.

We want inclusive policy. That means our efforts may shift from fighting for special laws to fighting for the inclusion of provisions for persons with disabilities in all national or international policies, plans, legislation or services. This means inclusive services instead of special services; community-based services and support to families instead of institutional centralism.

2. DEFINING THE PHILOSOPHY AND ETHICAL FRAMEWORK WE WANT.

We seek a philosophy that respects the person as a holistic unit included in a social network. We want a framework that sustains

the well-being of persons and families and the fulfilment of their *real* needs. We want a framework based on respect for life and human differences. Finally, we seek a model that respects individual cultural identities — a model with which we can begin to identify culturally.

3. DEFINING WHERE THE FOCUS SHOULD BE.

The focus should be on visualizing and strengthening the abilities and not the disabilities of the person, and recognizing that a disability is largely the result of a disabling environment. The focus should be on the best interest of the child and the family as opposed to the interest of a particular institution, even one that works on behalf of the child. Often the interests of institutions interfere with the interests of the person.

4. WHO SHOULD BE THE ACTORS IN THE PROCESS.

The proposed model is a process that moves from the identification of needs and problems to the determination of priorities, strategies and actions. We believe the focus should be on strengthening community-based strategies that allow the participation of families and persons with disabilities in the process. But in order that the model have real impact and sustainability, cooperation and flexibility of roles should be allowed, with governments and community members working hand in hand to develop the best policies.

People in these roles should become permanent partners, with different responsibilities in different phases of the process. There should not be pre-eminence or superiority of any one role. For example, families and community groups have the *real* needs. Governments have the systems and responsibility for policies. Professional have technical know-how (though not all of it). They must be partners.

Partners in the process need mutual respect and valuation. They need the insight that achievements are realized step by step

and that a process of growing should not mean losing sight of the rules of balance and respect inherent to any social development process. There is the risk that stages might be pushed too quickly or codes of cultural realities distorted. And there is the risk in any process that institutional interests come ahead of the interests of persons with disabilities.

An example of partners undertaking a process of change is the Partnerships for Community Living project. The partners are the Canadian Association for Community Living (CACL), the Inter-American Confederation of the International League of Societies for Persons with Mental Handicap (CILPEDIM) and the Inter-American Children's Institute (IIN), with the sponsorship of the Canadian government. The project was designed to develop this new model in three years. We are testing the model in its different phases. It is like a living cell working within our communities in the Americans — a social laboratory. Families, the government, professionals, local institutions, international organizations and youth with disabilities are cooperating.

THE COMPONENTS OF THE PROJECT

1. TRAINING AND COMMUNITY DEVELOPMENT:

- to identify needs and problems, to prepare a framework, to design policies and programs;
- to develop good policy makers and service providers.

2. RESEARCH:

- to provide a sound basis on which to set priorities and strategies.

3. INFORMATION:

- the key to equality and negotiation.

FINAL REFLECTIONS

The challenge is significant. Our job is not easy. It involves courage, understanding and a learning process. Frustrations and failures will be part of it, as will joy. Dostoevsky said: "To take a new step forward is what we fear the most. But what we should really fear is to be passive and indifferent to human needs." We need generous and brave people who are not afraid to take risks and dream and who do not fear change.

The following poem symbolizing a key element that underlies our vision was written by a 12-year-old Canadian boy, Richard Janzen, and is taken from the book *Miracles*:

When I walk home from school

I see many houses

They are warm and comfortable

But other people's houses

I pass without notice

Then I walk farther

I see a house, *the* house

That speeds my pace, I bubble inside

It is *my* house.

CHAPTER 15.

Concepts of Development and Maturation: Barriers to the Rights of the Child?

BY LUIS LOPEZ MOLINA, COSTA RICA

> *Considering that the child,* ***by reason of his physical and mental immaturity,*** *needs special safeguards and care, including appropriate legal protection, before as well as after birth ...*
> ***Preamble to the Declaration of the Rights of the Child, 1959***

> *Bearing in mind that, as indicated in the Declaration of the Rights of the Children, "the child,* ***by reason of his physical and mental immaturity,*** *needs special safeguards and care, including appropriate legal protection, before as well as after birth" ...*
> ***Preamble to the Convention on the Rights of the Child, 1989***

After reading these statements, a whole series of troubling questions arise:

- Do children have the right to be respected according to their particular developmental and maturational status?

  If so...

- Why is this right not mentioned in the *Convention on the Rights of the Child?*

If the justification for the rights of children to special protection and care comes from the underlying premise of their state of deficient maturity ...

- Does society have any responsibility in creating this deficit or is it generated intrinsically and spontaneously in children?
- What, then, is the condition of "doubly deficient children" — first because of their lack of maturity; and, second, because of their condition as disabled?
- Is it not simply their condition as people in particular and unique states of development and maturation that, by themselves, identify children and give them access to special rights?

Unfortunately, I do not have the answers to all these questions and this causes anguish, because the children are waiting.

In this paper, I would like to share some ideas about concepts of development and maturation because I believe that these very concepts create conditions that limit the access of children to their own rights. Traditionally, according to a hegemonical perspective, the development and maturation of children have been viewed as processes which, ideally, will allow them, as adults, to fulfill their responsibilities as citizens.

In general terms, the underlying concepts of these processes refer to chronological changes, continuous and irreversible, that occur in an organism as the unfolding product of an intrinsic plan which directs molecular, structural, physiological and psychological transformations. As an apparently logical consequence of the occurrence of these changes, it is possible to establish sequences or chronologies that allow us to recognize, with a high degree of certainty, the stages of "normal" growth and maturation.

According to this view, the role of experience or environment in these processes seems to be minimal: experience and environment can possibly modify, to some extent, the manifestations of the intrinsic characteristics of individuals but without being, at any moment, responsible for them. At this point it would be pertinent to ask the opinion on this matter of people who have been exposed to nuclear disasters, lead poisoning or famine, or even those who have been segregated as a result of their "intrinsic characteristics".

The *Theory of Preformation*, prevalent in former centuries, postulated the existence of a *homunculus* in the fertilized egg and understood the developmental process as the unfolding of pre-established structures and functions. The irony, as mentioned by Connolly and Prench,[1] is that the Theory of Preformation seems to have been revived in modern science. Today, founded on a solid scientific base, we might be able to speak of a "theory of genetic preformation". Today, the homunculus is no longer irrational magic. It is called DNA.

The above-mentioned vision seems to be the foundation for assertions that the processes of development and maturation and, further, the psycho-social state of people can be scientifically standardized and evaluated by merely correlating two elements: chronological age and personal performance. The latter is understood as the pragmatic, outward expression of the human structure, function and capacity in a moment and context usually predetermined by evaluators, be they professionals, institutions or states.

Consequently, if we were afraid to be identified as detractors from the truth, we need to agree with at least four principles. First, we must accept the validity of so-called universal concepts of normality and maturation based on an accumulation of scientific knowledge, which is assumed to be certain, concrete and tangible. Second is the legitimization of the existence of

the "abnormal" and those deemed "abnormal" and of "immaturity" and those deemed "immature". Third, we must accept that states of abnormality and immaturity are basically inherent to the individual and that the role of experience — be it in environmental, societal or national or transnational states — in the genesis of people's development is only secondary. Finally, we must assume as certain the hegemonic right of the processors of knowledge to decide which policies or actions are pertinent for redemption, remedy or protection of those populations who, because of their atypical conditions, are needy. Given this context, it is not surprising that children's access to their rights is subject to the notion of their inherent condition of insufficient maturity, giving society the opportunity to deny any of its responsibility in the historical construction of this disadvantage and legitimizing its role as redeemer.

REPERCUSSIONS ON CHILDREN WITH DISABILITIES

SERVICES

Traditionally, at least in many Latin American countries, most public and private organizations that have developed programs to address the needs of children with disabilities, have done so based on the concepts of development and maturation mentioned earlier, as well as on experiences in assistive medical care and formal education. The resulting services have usually been unable to nurture and support the needs of children with disabilities. These services have sometimes, in fact, been counter-productive, promoting the segregation and disrespect of the basic rights of children with disabilities and their families.

Services developed by these organizations typically respond to needs identified by the professionals who plan and execute the

programs. This arrangement tends to ignore the context of the issues facing individuals with disabilities and their families, and their social realities. The "centralization of services" that professionals promote tends to create vertical, rigid programs. As a result, to operate well the programs require a homogenous group of service recipients and fail to meet the unique needs of children and their families. Because of this institutionalized approach, operating costs are high, which reduces the services' abilities to address the extensive needs of disadvantaged individuals and limits access by less privileged people. The service professionals' concept of saving, "fixing" and normalizing people promotes various forms of institutionalization and segregation, creating barriers to integration and full participation.

Finally, when these service models are used to identify individuals and groups at risk with the goal of promoting these people's processes of development, they are usually ineffective. Their focus limits them to consideration of only biological factors. It ignores social and environmental factors which have been understood to cause many processes historically responsible for more disabilities and disadvantages in individuals.

THE PARTICIPATION OF THE FAMILY

Generally, the communities requiring services or access to specialized personnel have ways of supporting and helping their children with disabilities. These ways seem to be developed by leaders in each social group or community, giving the community a unique geographical and cultural identity. When professional services are introduced, the community's right to play a key role in creating processes of development for their members with disabilities is frequently taken away because service models clash with their own culture. Services can be put in three categories according to how much participation of parents they allow:

1. Programs where all care of, and dealings with, children with disabilities are the sole responsibility and claim of professionals and people in the pertinent public sectors — Health, Education or Social Services. The characteristic verticality and paternalism of this type of service puts parents in an extraneous and fundamentally passive role. They are essentially excluded or excused from the responsibility of caring for their children. The possibilities of interaction between the home and the institution are minimal, which obviously functions to encourage parents to act as mere legal guardians.

2. Programs operating on the obviously questionable premise that a child with a disability almost invariably implies the presence of a disabled or dysfunctional family. For this reason, these programs are directed not only to caring for children with disabilities, but are usually developed and directed towards prevention of, and caring for, the dysfunctional behaviour that can arise in the nuclear family. Support groups, directed by professionals or parents, arise from a desire to "fix" the nuclear family and, by extension, the community by looking for a better understanding of family problems.

3. Programs in which parents share in the care of their children. In these programs, parents are given technical training related to the problem of their child. They learn therapeutic methods that allow them to contribute to, and follow, the intervention of the professionals and specialists.

Access to this third level of participation seems to emerge from three directions:

1. From the acquired conscience of some institutions and

professionals who discourage the parents from acting as mere guardians and encourage a greater degree of participation in the therapeutic processes.

2. As a result of many parents' determination, despite institutional philosophies or practices, to assume a committed role, frequently becoming experts in the particular situation that affects their family member.

3. As a result of institutions' inabilities to keep up with the increasing demands on their services and the necessity to augment their levels of coverage. This seems to be the case, as in many countries today, where governments are looking to transfer a larger share of their responsibilities to communities in general and families in particular.

At this third level of participation there seems to be an emergence of therapeutic-families, parent-teachers and physiotherapist-mothers. The commitment to treatment often takes on the overtones of partnership, friendship and solidarity — in short, of love. Unfortunately, the first level of participation still dominates in most societies: the role of the parents is minimal and is rigidly dictated by institutions according to their theoretical models.

TOWARDS A NEW CONCEPT OF THE DEVELOPMENT OF CHILDREN

Man is an organism whose existence is a product of phenomena, influences and biological and social conditioning, which manifest themselves through actions and reactions in spite of, or in collusion with, their will in an incessant exchange of cause and effect ... Nature, work and experience make possible the evolution of man, rewarding his achievements, satisfying his needs and satisfying the practical demands of society. The basis

of these relations is economic but their result is, additionally, psychological, ideological and cultural. In this complex interaction of changes and influences one cannot establish precisely when and how the material elements transform themselves into ways of being and states of physical, mental and emotional health because, in reality, it is not about specific moments in time; instead it is an incessant passing of moments which never stop and whose cultural movement is, precisely, one's life.

Carlos Castillo Rios, 1979[2]

It would be pretentious to attempt to define new concepts of development and maturation. Castillo Rios does this eloquently. However, there should be a commitment to open up the concepts of development and maturation of children and to stop legitimizing the "abnormal". This commitment should be shared between social and political sectors. No one group or one sector should monopolize this task. The following ideas are presented only as principles I feel are important to take into consideration.

The concepts of development and maturation and their implementation should incorporate the idea that these processes are a product of the interaction and arrangement of biological, environmental and socio-cultural factors. Therefore, in the processes of development and maturation, the basic structures — the individual and collective genetic bank — are influenced by ecological, economic and political factors and by social conscience and conduct. In other words, these processes are products of social constructions which occur along a temporary and dynamic axis.

The individual, the family and the community should act as communicators, informers and constructors in the processes of development and maturation. They must regain their voice and

their rights, taken away from them by service models that clashed with their cultures and histories. The concepts of development and maturation should be defined by and in each particular community or society.

In the existing model, the concepts of immaturity, abnormality, deficiency and even disability have emerged as odd products of a biological sciences and structuralism. In the new model, these concepts will be understand as "*critically evolved states and situations*". In other words, they must be seen as products of the continuing interaction between: the particular *potential development of each child*; ecological, economic and political factors; and social conscience and social conduct (*dynamic manifestations of the development of each individual*).

Programs and other efforts to promote children's development and maturation and the process of learning should identify and promote each child's *diverse and unique expressions of development*.[3] All efforts in this direction should be seen as holistic social processes that seek to maximize the evolving potential of each child. The factors contributing to the development of each child's potential should be understood as a "an interrelated continuum of potential". These interrelated factors, which should not be considered in isolation, include, on one hand, the child's age, economic situation and particular condition in the process of evolution and, on the other hand, the social rules of behaviour and the lifestyle of the family, community and particular culture.

The preoccupation of societies with the development of children should not be focused on states of "immaturity" and "abnormality". Instead, societies should focus on diminishing the gap between an individual child's potential for development and the dynamic, outward expression of this potential. If we subscribed to quantitative theories, we would venture to say that the measurement of this gap could become an indicator of social justice.

A new model of the concepts of maturation and development requires a shift in attitude and movement away from the existing structuralist perspective. This change should have an impact not only on those who plan and provide the services but also on the entire community, so community members can actively participate in the process. The consideration of an individual child's needs and cultural background will permit a more equitable, just and effective use of resources. It could also create greater access to more responsive, individualized services for children and their families.

We must develop new strategies and processes that legitimize and promote the true development of children. These strategies must be developed coherently in each community according to that community's geographical and cultural context. In this way, programs and actions promoting children's development will also become strategies of social participation, of democratization, of knowledge, of empowerment and, above all, of respect for the rights and dignity of each person, regardless of their particular state of maturation and development.

The Latin American humanist and writer Alejo Carpentier, once said, "... and in this way, the future opens up a space to foster the capacity for solidarity and profound respect for individual differences."

NOTES

1. K.F. Connolly and G.F. Prench, "Maturation and Development: Biological and Psychological Perspectives", *Clinics in Developmental Medicine*, No. 77/78, Piladelphia: S.I.M.P., Lippincot Co., 1981.

2. Carlos Castillo Rios, *Medicina y Capitalimo: Proceso a la medicina lieral*, Lima, Peru: Ediciones realidad Nacional, 1979.

3. It is obvious that we are trying to avoid using the terms *abnormal, immature, deficiency* and *disability*.

CHAPTER 16.

Policy As If Disability Mattered

BY MELANIE PANITCH, CANADA

I recently attended a lecture by Gloria Steinem, a prominent spokesperson in the United States for the feminist movement. She described a strategy she uses to address the familiar concerns of women, a strategy of "reversal". This involved "opening the other eye" and challenging the "remedial vision" that regards most subjects in a singular way. For women this would mean looking at the world as if women mattered; for men this would mean looking at the world as if they were women. She did this, she said, to gain new perspective and reach deeper understanding.

I began to think about what new perspective and understanding might emerge in the arena of social policy if the same strategy were applied. What if the familiar concerns of people with disabilities were addressed by "opening the other eye" and challenging this same "remedial vision". This would mean looking at the world "as if children and youth with disabilities mattered". For people *without* disabilities this would mean looking at the world as if they were disabled. What might happen if those who determined what a society would provide for its citizens had personal experience and knowledge about living with a disability? What policies might emerge for children and youth with disabilities from a perspective in which disability mattered? What impact might that have on the communities in which children live?

The particular policy I would like to consider from this perspective, as if disability mattered, is that determining the provision of child care in Canada. Child care can be defined by answering four questions. The first question relates to how children are viewed in Canadian society. Determining the best arrangements to care for a nation's children is an old problem to which different societies have found a range of solutions. The value placed on children by different societies determines the policies related to child care. The distinction has been made between "traditional societies" and "modern societies".[1] In traditional societies children are regarded as an asset from a very early age because they contribute to the social life of their group through sibling caretaking and simple farm work. In addition, they are expected, as adults, to provide for their aging parents.

In modern societies the period of dependency is prolonged. Children do not represent value until they reach adulthood. Even in adulthood, their value is represented differently because they are not expected to care for their parents. Care of the elderly has become more the responsibility of the community at large than the natural family. The organization of work is also more regimented than in traditional societies, with the conflicting demands experienced by parents as paid workers leaving little room for caretaking.

This leads to the second question: what functions do child care serve? Many people have argued that there is a gap between the needs of children and the resources available. In Canada, the demand for child care far outstrips the supply, primarily due to the country's inability to keep up with the accelerated rate of mothers' participation in the work force. Projections for 1996 suggest that 80 per cent of Canadian women will be in the labour force. Nearly two-thirds of women with children under age six are working outside the home and more than 70 per cent of preschool children are participating in non-parental child care arrangements.[2]

Over the past two decades, the number of regulated (licensed, inspected) full-time spaces in child care centres grew by an annual rate of 10 to 16 per cent, yet long waiting lists exist.[3] Similar economic forces are driving non-parental care arrangements in many other countries. Indeed, historical and cross-cultural research has found that nowhere have the basic demands for maternal child care been driven by forces other than economic.[4]

Driven by economic need, child care has been used to serve a number of purposes.[5] The protection of class interests has been one of these purposes. The earliest day care centres in Canada such as the Montreal Day Nursery of 1900 were created to respond to the need for domestic servants. Care arrangements were provided for the children of mothers working in the service of wealthy families. The hours of operation were deliberately controlled to ensure employers of the domestic help received a "fair day's work".[6]

The Canadian government became involved in establishing and funding child care facilities during the Second World War to attract women to work in war-time industries. This support dissipated when men were demobilized. More recently, child care has again served to encourage female labour force participation, allowing women greater economic independence.

A third function of child care is to acculturate new immigrants by introducing parents to Canadian "ways" ranging from the provision of health care to how children need to be dressed to survive Canadian winters. Fourth, the provision of child care provides a way out of the poverty trap by encouraging women to seek job training or paid employment in order to cease their reliance on welfare. Finally, child care serves the important purpose of enriching children's lives. In Canada, the recommendations of the government-appointed Cooke Task Force on Child Care called for the recognition of day care as a benefit for all Canadian families when it reported in 1986, signifying a break with the welfare framework.[7]

The third question in defining child care involves policies governing its provision. This tests the value of the child in society because it poses many hard questions: How should child care be divided between parents and society? How much do parents consider "worth" paying for their child's care? What proportion of public spending should be dedicated to child care?

At the present time Canada does not have a national child care policy, unlike education and health which are universally accessible and publicly funded. The federal government's role is restricted to a number of funding mechanisms.[8] The provincial and territorial governments are responsible constitutionally for child care and play the lead role in program design and delivery. As a result, child care varies significantly across the country. On the positive side of this arrangement, policies have been developed that reflect the needs of citizens living in geographically diverse areas. On the negative side, these differences continue to persist without a comprehensive, nationwide policy direction.

The fourth question has to do with the impact child care policies in Canada have on children with disabilities. Families struggling to find suitable care for their children with disabilities find it astonishing to learn that, despite the variations across the country, parents, no matter where they live, encounter many of the same obstacles when they seek child care.

Integrated child care is not legislated anywhere in Canada. Some centres are accessible because the director and staff make a personal commitment not to turn away any mothers. In some provinces, supportive bureaucrats will exercise their authority to encourage integration, while in others, operating an inclusive program means going around the regulations. Competing claims push integrated child care towards the bottom of the government priority list.

What do parents find? They find a system that is not working for families. Lack of funding for child care results in

waiting lists and inadequate support services. Parents find a lack of coordination between government departments, regional differences within a single province and different levels of staff knowledge about benefits and programs. They find that even when a space can be found, access can be a hurdle. One mother recounted:

> *When I looked for day care for Sandy he was not yet walking. Without even seeing him the director said, "Sorry, we can't accommodate special needs. This program operates on two levels and we can't take a child who is going to hold us back". I didn't question her decision — I really did not want him there if that was indicative of their attitude. Two is a little young to experience discrimination.*

Parents find centres that set their own admission criteria. To ensure their children are eligible, parents sometimes have to portray their children negatively, cloaking them in labels to qualify for services.

Parents also find the cost of child care a major disincentive on top of the additional disability-related costs associated with the extended use of diapers, the need for specialized equipment and time away from work to attend countless appointments. And, for every child not in their neighbourhood centre, transportation is an issue in both rural and urban areas.

When families do gain access to a program, they are likely to find programming that does not meet their needs. Many families are offered a half day of care that denies the child's mother the support she needs in order to hold a job. This limitation adds further economic hardship.

The diversity of Canadian society creates a requirement for human services to respond to families whose culture, language and experience differ significantly from the dominant culture.

This is not always easy. As one parent observed:

> *When the bureaucracy functions in a language other than your own, when you are asked to give out information that in your culture is considered private and when you are faced with the possibility of handing your child over to complete strangers (culturally, racially, linguistically) who don't understand your background or your desires or aspirations for your child, the requirements for adjustment can be overwhelming.*

An "uphill battle" is how one mother described the impact current child care policies have on families caring for children with disabilities. In addition, the obstacles that prevent access to quality child care for children with disabilities fall with disproportionate weight on women. To them, the radical changes in women's roles and expectations of the last few decades do not apply.

BUT *WHAT IF* DISABILITY MATTERED?

If disability mattered, more equitable alternatives could be found. A more coherent national approach to child care could be designed, with standards, so that all children could be included, regardless of ability, ethnicity, income or gender. A full range of services would be available and all children would have access, no matter where they lived, to quality child care. Child care would be affordable because it would not depend on parent fees but, like health and education, would come with the rights of citizenship in Canada. Parents would be recognized as the primary nurturers of their children and ample opportunities would exist for them to be involved in their child's program.

But one has to wonder, even if all this were to be achieved and children exposed to the best child care programs possible, would this be enough? There has to be good child care but it has to be part of a larger web of provision. Other inclusive policies would also need to be in place to support children, their families and their communities.

WHAT POLICY INITIATIVES MIGHT OTHER JURISDICTIONS UNDERTAKE — IF DISABILITY MATTERED?

If disability mattered, departments of education would take on the delivery of head start and early interventions programs targeting all children. This would ensure that children considered at risk according to the traditional definition would continue to receive service. In addition head start and early intervention would also target children with behaviours that would result in intolerance and disrespect for the rights of their peers with disabilities. Program evaluations would measure whether, as a result of the intervention, children were grasping the concepts of compassion, sensitivity, acceptance and equality.

If disability mattered, ministries of culture would support and fund an international film festival celebrating the history of disability and promoting the enrichment of disability culture throughout the world. Film makers, actors and writers would be invited to attend and promote the series.

If disability mattered, senior administrators in the media and communications industries would articulate strict guidelines prohibiting the portrayal of children and youth with disabilities in demeaning and pitiable images on public and private television. Charitable telethons would be disallowed. Instead the air time would be used to celebrate best practices in inclusive education. Phone lines would operate as before, callers could dial in, express approval and contribute money to schools that were making a positive difference.

If disability mattered, the departments of public works would announce prestigious architectural competitions challenging architects to create alternate futures that would forge contemporary design with social commitment. Access to all public buildings would be a given.

If disability mattered, policy-makers in fitness and sports would succeed in persuading the board of directors of Special

Olympics to redirect their vast resources to local recreation programs. With resources, local programs would be able to expand and encourage broader community participation. Any athlete truly demonstrating Olympic talent and willing to train and compete could do so while others could explore possibilities for achieving their personal best.

If disability mattered, departments of labour and industry would ensure that workplace child care was available for all employees and, of course, accessible to all children. "Family-friendly" policies would be instituted to support parents to work part time or at home, or to have flexible work hours and parental leave. Where such policies were not already in place, union negotiating teams would introduce these items as top priorities in their next round of collective bargaining.[9]

If disability mattered, policy makers with responsibility for women's issues would begin to tackle traditional economics. Critical changes would be made so that the work women do could at last be counted. Major targets for change would be the census, which determines what is visible, and the national system of accounts — the Gross National Product and Gross Domestic Product, which decide what is valuable. Until these shifts occur, women taking care of their own children in their own home will continue to be viewed as "not working". Therefore, they will neither be counted in the census, nor will their labour be calculated in the national system of accounts. Without a classification system that recognizes labour performed in the home as work, there is no gathering of information that might influence policy and programs about the needs of women who work in the home. Policy, as if disability mattered, would render care-giving visible.[10]

If disability mattered, ministries of colleges and universities would redesign course curricula for all health and allied health professions. Textbooks on the effective management and control of difficult behaviours, with their underlying bias on conformity,

outlining deficits, pathologies and syndromes would be replaced. Instead, students would be encouraged to be more open-minded, reflective and to engage in considerations of choice and self-determination. One compulsory reading might be from Jane Wagner's *The Search for Signs of Intelligent Life in the Universe*, words uttered by Trudy, a bag lady and social historian, who is examining the latter half of the 20th century:

> *After all, what is reality anyway? Nothin' but a collective hunch. My space chums think reality was once a primitive method of crowd control that got out of hand. In my view, it's absurdity dressed up in a three-piece business suit. I made some studies, and reality is the leading cause of stress amongst those in touch with it. I can take it in small doses, but as a lifestyle I found it too confining. It was just too needful; it expected me to be there for it all the time, and with all I have to do — I had to let something go.*[11]

However, as if that were not enough of an agenda, there is a need to remain vigilant. Economic circumstances threaten to turn the clock back.

There is a further caution. When a program or initiative becomes successful, it may become universal. Once universal, there is the risk it will lose the focus that created it in the first place. The history of recreation programs for children in North America illustrates this phenomenon.[12] The "play movement" began in Boston in the 1890s and was inspired by the recognition that poor children in 19th century American cities had nowhere to play but the streets. It focused on providing a safe place for children to play near where they lived. For the first 25 years, sandboxes and toys were set up in poor, congested areas. But the idea of green and pleasant places caught on. By the beginning of the First World War, small parks were springing up in middle

class and suburban areas, taking on the dimensions of recreation centres, not only for children but for adults too. The play movement succeeded so well it resulted in universal availability of what had begun as a service for the poor. However, a 1928 survey in New York City found a significant discrepancy between the adequacy of parks and playgrounds in the congested areas and in the more affluent areas. In 1968, "poor recreation facilities and programs" were cited as contributing to the ghetto riots of the 1960s. Once universalized, the focus on those children who needed the concept most was lost. History is useful if we can learn from it.

This year, 1994, marks 40 years since the court decision in *Brown* v *The Board of Education* affirmed school segregation as separate and unequal. The court found that segregated schools generated "a feeling of inferiority as to [children's] status in the community ... unlikely ever to be undone". But hindsight shows that the court's focus on improving children's self-esteem ignored the social and economic issues needed to make it meaningful. Therefore, 40 years later, little has been gained in terms of educational equality. Micaela di Leonardo, an American educator, asked whether, in 1994, Brown still mattered:

> *Rather than following the Court psychologism and continuing to worry about children's self-esteem we would do better to fight hard for the democratic principle of radically equalizing all public school funding. Children's feelings and culture, in an egalitarian, well-funded environment, will take care of themselves.*[13]

How Canada's children and youth develop into adults has enormous implications for our society. How children are valued and families supported has enormous implications for the future. A child's abilities, cultural background and nationality do not change what we already know: that all children have the same

need to be valued and supported to grow and develop. Solutions can be found by "opening the other eye" and challenging the "remedial vision". Looking at the world *as if children and youths with disabilities mattered* is not beyond the reach of enlightened social policy.

NOTES

1. Anders Broberg and C. Philip Hwang, "The Shaping of Child-Care Policies", in Michael Lamb, Kathleen Sternberg, C. Philip Hwang and Anders Broberg, *Child Care in Context*, Hillsdale, New Jersey: Lawrence Erlbaum Associates, 1992.
2. Premier's Council on Health, Well-being and Social Justice, *Yours, Mine and Ours: Ontario's Children and Youth*, Toronto, Ont.: Queen's Printer for Ontario, 1994.
3. H. Clifford, "Child Care in Canada - 1990", *Vision*, Vol. 10 (April), p. 9.
4. Michael Lamb and Kathleen Sternberg, "Sociological Perspectives on Nonparental Child Care", in *Child Care in Context*, 1992 (see n. 1).
5. Ibid.
6. Patricia Schulz, "Day Care in Canada: 1850-1962", in Kathleen Gallagher Ross, *Good Day Care: Fighting For It, Getting It, Keeping It*, Toronto, Ont., Women's Press, 1978.
7. Hillel Goelman, "Day Care in Canada" in *Child Care in Context*, 1992 (see n. 1).
8. L'Institut Roeher Institute, *Right Off the Bat*, North York, Ont.,: Author, 1993.

9. Premier's Council on Health, Well-being and Social Justice, *Yours, Mine and Ours*, 1994, pp. 19-20 (see n. 2).

10. Gloria Steinem, "Revaluing Economics", in *Moving Beyond Words*, New York: Simon and Schuster Inc., 1994.

11. Jane Wagner, *The Search for Signs of Intelligent Life in the Universe*, New York: Harper and Row, 1986, p. 18.

12. M. Jones and D. Offord, "After the Demonstration Project", paper presented at the 1991 annual meeting of the American Association for the Advancement of Science, Washington, D.C.

13. Micaela di Leonardo, "Does Brown Still Matter?" in *The Nation*, May 23, 1994.

RALPH

BY LORRAINE SILLIPHANT

In our family there are three children: our two daughters, Carol and Dianne, and Ralph, our youngest. Ralph's life has been marked by conflicting experiences of acceptance and rejection—acceptance and close, caring relationships with his family and friends, and rejection by the systems outside our family. For example, because of a psychological assessment, he was not accepted in a special toilet-training program when he was five years old. We moved into a new town where he was not accepted into the regular school his sisters attended because of the way he looked and some numbers attached to him. He had to apply and wait to get accepted into an auxiliary class in a portable in back of the school. It was again a struggle to get him into regular class from a segregated class in high school.

This sounds like a story of rejection but it isn't because the struggles don't really matter. When we talk about them it seems as though we live in an excluding society. However, it hasn't made much difference in Ralph's life because he has been accepted in a family that really cares about him and he has many friends. In the instances where he has been excluded and rejected, his family and friends have accepted him and supported him. The town has recreation activities which he is supported to attend. This is where his life really happens. Although he was not welcome in some areas, he was welcome in others.

He is now 25 years old and has been working in a government department for two years. The people in his life, such as his co-workers, support him to have this job. We feel that the focus must be on the support from, and the *relationships* with, family and friends. It is not the programs that are important but the relationships that are meaningful. Life is full because he has a job, something meaningful to do, his friends and co-workers — relationships. He telephones his sister continuously to connect. Barriers make a person feel less valued but what counts is relationships.

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- **The Power to Choose:** An Examination of Service Brokerage and Individualized Funding as Implemented by the Community Living Society, 1991
- **Right Off the Bat:** A Study of Inclusive Child Care in Canada, 1993

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As If Children Matter:
Perspectives on Children, Rights and Disability

"The infant was put in a hospital corridor with a sign on the incubator saying 'Nothing by mouth', and after 11 days the infant died of starvation."

"It is estimated that more than four million children under five years of age in Latin America and the Caribbean die every year from disease."

"To me the institution was a prison. I always felt that my son was at war trying to survive."

...excerpts from *As If Children Matter*

All children, including children with disabilities, have rights—the same rights, rights upheld in internationally sanctioned documents. Yet this is not well known or understood. *As If Children Matter* is a collection of articles from people throughout the Americas examining the rights of all children, and in particular children with disabilities. The contributors look at such issues as what these rights are and how their denial affects the lives of children; the impact of an increasingly fast-paced, morally dazed world on families and children; how poverty, a lack of services and institutionalization affect children and their families; and how policy influences children's rights to justice, medical treatment, day care and education. Poignant, insightful and honest, the articles in this collection call for the rights of children, particularly children with disabilities, to be recognized and upheld in policy and practice around the world — in a manner that clearly says "children matter."